

A GROUNDED THEORY STUDY OF THE EXPERIENCES, PROCESS, AND TRANSITIONAL
NEEDS OF PEOPLE WITH AUTISM

A Dissertation Submitted to the College of
Graduate Studies and Research
In Partial Fulfillment of the Requirements
For the Degree of Master of Science
In the Department of Community Health and Epidemiology
University of Saskatchewan

By

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ABSTRACT

The overall purpose of this qualitative, constructivist, grounded theory study is to gain a clear understanding of the experience and process of transition for people with autism during the stage of emerging adulthood. Specifically, the objectives are: (a) to gain an understanding of the lived experiences and development processes of individuals with autism during their transition from youth to adulthood; (b) to construct a substantive theory of the experience and process of this transition, grounded in the experiences of people with autism and other stakeholders; (c) to identify any gaps or deficits in governmental or nongovernmental support that, if ameliorated, could ease an transition into adulthood of people with autism.

This study employed qualitative analysis, using constructivist grounded theory. Data were obtained through in-depth interviews with two groups of participants, including parents of people with autism and professionals involved in service-providing organizations. Twelve interviews were conducted; two of the ten participants were second interviewed. Participants were selected from Saskatoon using the snowball method.

It is revealed from this study that the main concern of people with autism was “resistance to change”. Properly managing their transition in to adulthood addresses this concern, helps them feel relaxed, and may prevent them from engaging in socially unacceptable behavior. The theory developed from this study describes 6 processes of effective transition: (a) make a plan; (b) introduce change gradually; (c) communicate effectively; (d) work in a team; (e) develop a supportive community; and (f) retain support staff. More individualized programs are needed for people with Autism Spectrum Disorders (ASDs), and existing funding policies should be reviewed. Also, they

would benefit from vocational training, residential facilities, more funds, trained staff, and trained Education Assistants (EA).

It is anticipated that the knowledge gained from this study will provide information on transition management. This research, therefore, is particularly beneficial to the people with autism and their families, as well as professionals working in this field. This study will also be useful in reviewing the policies and programs of government and nongovernment organizations in the field of autism. In its application, this study aims to contribute to both the research literature and existing programs on autism.

ACKNOWLEDGEMENTS

I want to thank my supervisor Professor Nazeem Muhajarine, committee member Dr. Lorraine Holtslander and Committee Chair Dr. Bonnie Jenzen and for their encouragement and guidance. They gave me excellent support throughout this learning process. Also I would like to thanks external examiner Brenda Kalyn for her detailed feedback on my final thesis. Thanks to autism consultant Mr. Ashok Ukia. He helped me find participants for this study and took time throughout the research process to discuss various issues regarding autism. I want to thank the participants in this study for giving their time, and sharing their experiences and skills. They were essential to creating knowledge on this issue. Thanks especially to my wife and daughter who continue to support my study.

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CHAPTER ONE

INTRODUCTION AND OVERVIEW

This chapter provides a brief overview of my research into the transitional needs of people with autism in Saskatoon, Saskatchewan. It provides a brief introduction; the purpose, objective, methodology, and significance of the study; and also highlights the possible benefits, limitations, and summary of the study.

1.1 Statement of the Problem

Autism spectrum disorder (ASD) is a range of complex neurological conditions, which have enduring implications for individuals and their families. One in 93 children in Canada have ASDs; 1 in 88 children in the US are affected, (Autism Spectrum Disorders, 2013; Baio, 2008). Studies show that the prevalence of ASDs has been increasing over time (Baron-Cohen, Scott, Allison, Williams, Bolton, Matthews, & Brayne, 2009; Fombonne, 2003, 2005). For instance, in the US, the prevalence of ASDs in the general population increased by 23% for the 2-year period 2006–2008, and by 78% during the 6-year period 2002–2008 (Baio, 2008).

Autism is a wide-spectrum disorder. Two people with autism will not have exactly the same symptoms. There are a variety of symptoms; some are mild, while others are severe. How a person with ASD interacts with another individual is quite different compared to the rest of the population. They may be over-sensitive or under-sensitive to sounds, textures, tastes, smells, lights or colors. Some people with autism are able to live independently, but others may need support throughout their life.

Transition to adulthood is an important phase, a time when people with autism need special attention and support from their family and service providers. Adolescence is stressful enough for an average person; this transition is even more difficult for someone with autism. People with autism prefer to follow a routine and are therefore threatened by any kind of change. Sommons (2010) argues that, due to the rapid rise in autism prevalence since the mid-eighties, more and more children with autism are left to approach adulthood without comprehensive resources to facilitate their transition. It is essential that a professionally, carefully designed plan be in place to ensure a successful transition. Unfortunately, there is a lack of research into effective facilitation strategies for people with autism in Saskatchewan, Canada (Loutzenhiser & Sluth, 2012).

1.2 Purpose and Objectives of this Study

The overall purpose of this qualitative, constructivist, grounded theory study is to gain a clear understanding of the experience and process of transition for young individuals with autism during the stage of emerging adulthood. Specifically, the objectives are: (a) to gain an understanding of the lived experiences and development processes of individuals with autism during their transition from youth to adulthood; (b) to construct a substantive theory of the experience and process of this transition, grounded in the described experiences of parents and professionals work for the people with autism; (c) to identify any gaps or deficits in governmental or nongovernmental support that, if ameliorated, could ease a people with autism transition into adulthood.

1.3 Summary of Research Methodology

Grounded theory methodology was employed in this study. Grounded theory is a systematic methodology involving the discovery of theory through the analysis of data. According to Glaser and Strauss (1997), grounded theory is an inductive methodology that allows researchers to generate a theory from the perspective of participants by listening closely to the ideas of those participants. Glaser (1978) argues that grounded theory allows researchers to identify key explanatory concepts and their relationships. Creswell (2005) states that grounded theory is a means for an author or researcher to explain a basic social process. Constructivist grounded theory was rooted in pragmatism and relativist epistemology. It assumes that theories are co-constructions by the researcher and his participants, as a result of their interactions in the field (Charmaz, 2000, 2007).

This study employed qualitative analysis using constructivist grounded theory. Data was obtained through in-depth interviews with two groups of participants: parents of people with autism and professionals involved in service-providing organizations. Twelve interviews were conducted with ten participants, where two of participants were second time interviewed. Participants were selected mainly from Saskatoon using the snowball method. Data was analyzed according to grounded theory, which includes initial, focused, and theoretical coding.

1.4 Significance of this Study

I was working for people with autism in their residential facilities where they live. I had to assist both female and male individuals with autism. I had a chance to closely observe them and their transitions, and talk about their issues with their parents. My motivation for researching the area of transitional need for people with autism came from personal observations of the turmoil many parents go through during their children's transition to adulthood. Although families who have children with autism receive special education, referral, advocacy, recreation, social skills training, and adult residential services, no known studies have examined the experiences of the families receiving these services and the views of the professionals delivering the services. In my view, it is imperative to identify these transitional needs and address them in an effective manner. I found that the issue of transitional management for people with autism is an important area of study that can contribute to the vulnerable population. This study aims to contribute to a more comprehensive understanding of the experience and process of adolescence and the need for services for people with autism during this critical phase. This study may influence change by helping to identify areas of need during transition in a more effective manner.

1.5 Possible Beneficiaries of this Research

This research addresses a very important gap, which is the study of the adolescent transitional experiences and processes of people with autism. It is anticipated that the theory generated from this study will provide strategies on managing this transition. This research, therefore, is particularly beneficial to people with autism and their families, as well as professionals in this field. This study will also be useful in reviewing the policies and programs of government and nongovernment organizations in the field of autism. In its application, this

study aims to make a contribution, both to research literature and to existing programs for people with autism.

1.6 Dissemination of Results

Results from the study will be published in peer-reviewed journals as well as presented at academic conferences. A copy of the thesis will be made available to the public at the University of Saskatchewan. The researcher will prepare an executive summary of the research findings and submit it to relevant stakeholders in Saskatoon. The stakeholders include the research participants, researchers, and government and nongovernment organizations working on autism in Saskatoon.

1.7 Limitations

A constructivist, grounded theory study design allowed the researcher to gather valuable insight from the participants' perspective, while also recognizing the influence the researcher had on the data. This study involves 12 interviews with 10 participants, where five are parents of children affected by autism and five are people from service providing agencies. Although qualitative rich data was generated from the study, a sample size of ten will eliminate the possibility of generalizing the data. The experiences of particular individuals with autism or their caregivers are context-specific and unique for their situation. Therefore, this study will not generate any universal or extensive results. However, there are enough similarities among them that we may infer that the results of the research would be similar in other situations. The detailed nature of the results, however, makes them ideal for transferability.

A further limitation to this study is the fact that the researcher has interviewed parents. Their statements may not be an accurate reflection of the voice of their children with autism. In addition, the researcher has not addressed all types of people within the spectrum of autism

disorder. Finally, it is important to note that I have made a preconceived perception, that the transitional needs of people with autism has not been addressed properly, which led me to select this topic.

1.8 Definition of Terms

Autism Spectrum Disorder (ASD): Autism Society Canada (2014) describes ASD as a neurological disorder resulting in developmental disability, which affects communication, social understanding, behaviour, activities, and interest.

Pervasive Developmental Disorder (PDD): According to the DSM-IV-TR (American Psychiatric Association, 1994), PDD is a term used to express an umbrella of disorders characterized by pervasive and severe impairments related to communication skills, reciprocal social skills and/or the display of stereotyped behaviors, interests and activities. In the Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (DSM-IV) (Psychiatric Association, 1994), all ASDs are listed under PDD.

The following chapter reviews the current literature on the concept of autism and transitional needs for people with autism.

CHAPTER TWO

LITERATURE REVIEW

This chapter aims to present a thorough review of the current literature in the area of transition to adulthood for people with autism. The review begins with a brief description of the concept, prevalence, symptoms, and theories on autism. The discussion covers different aspects of this transition, which include concept, goals, process, and experience. This review also includes excerpts from the contemporary literature - pertaining to major issues for adolescent people with ASDs, gaps in services, and strategies for a more effective transition to adulthood.

2.1 Autism Spectrum Disorders (ASDs)

Autism Spectrum Disorders (ASDs) are complex neurological lifelong conditions that have significant impact on normal brain development. Parents of children with autism usually notice symptoms of autism onset between 12 to 18 months of age, and generally these children are diagnosed with ASDs between 3.5 to 5 years of age (Rogers and DiLalla, 1990; Autism and Development Disabilities Monitoring Network, 2006). Studies show that the prevalence of autism is five times higher in boys than in girls (Lotter, 1966). Usually, children with autism have delayed developmental milestones. Signs and symptoms include: no big smiles or joyful expressions by six months, no back-and-forth sharing of sounds, no babbling by 12 months, no words by 16 months, and a loss of speech or social skills at any age.

Five disorders grouped together under the term Pervasive Development Disorder in the DSM-IV are commonly known as autism. Autism is complex, certainly not a single, unified condition, but a family of overlapping, but not identical, disabilities. The diagnoses under the spectrum of disorders include Autistic Disorder, Asperger's Disorder, Pervasive Development

Disorder - Not Otherwise Specified (PDD-NOS), Rett's Disorder, and Childhood Disintegrative Disorder (CDD) (Paula, & Shouse, 2009). PDD-NOS and autistic disorders are considered to be the most severe among the disorders (Thompson, 2007). In this study, I will use autism or ASDs interchangeably to indicate any of the above-mentioned disorders.

So far, there is no biological marker available to diagnose ASDs (Bernier and Gerdt, 2010). Instead, diagnoses are done through direct observations and interviews with parents regarding their child's social, communicational, and restricted or repetitive behavioral domains. There are many different developmental screening tools that may be used by professionals, community service providers, and in some cases, parents, to identify children who might have developmental delays. These include: Ages and Stages Questionnaires (ASQ), the Modified Checklist for Autism in Toddlers (M-CHAT), and the Screening Tool for Autism in Toddlers and Young Children (STAT) (Autism Canada Foundation, 2014).

Many symptoms are common in individuals with autism, but each of them is unique. It is not necessary to have all symptoms in each domain to meet the diagnostic criteria. For instance, one child with autism may be good at maintaining eye contact during interaction, but cannot maintain age-appropriate behavior. According to the Diagnostic and Statistical Manual of Mental disorders (DMS-IV), a person must have 6 of the possible 12 diagnostic criteria, in which at least two are related to social impairments and one to communication impairments and behavior interests, to be diagnosed for autism (Yapke, 2003).

There are several major theories in conceptualizing autism. Weak Executive Functioning Theory indicates impairments in the ability to regulate cognitive and affective function. The areas of Executive Functions are: regulating emotions, responding to new information, and shifting

attention when required. Mind Blindness focuses on the dysfunction of recognizing and responding to the emotions of other people around them (Wheelwright, 2007). Most recently, the Intense World Theory attempts to explain all symptoms of autism as a sequel of the autistic brain's extreme reaction to stimuli. However, we still cannot clearly define autism.

Autism mainly affects communication, social interaction, and relationships. Children with autism often have restricted, repetitive patterns of behavior (Autism Spectrum Disorder, 2012). In the domain of communication, it appears that people with autism have delayed language development, difficulties in spontaneous conversations, presence of repetitive speech, and lack of pretended-play skills (Bernier and Gerdt, 2010). The core symptoms of autism are apparent in establishing reciprocal social relationships. People with autism have an impaired ability to engage in social relationships, which is demonstrated in various ways, such as an inability to display appropriate facial expressions, maintain eye contact, respond when called by someone, and respond to affection (Autism Canada Foundation, 2014). They also have a limited ability to develop appropriate peer relationships and, therefore, enjoy less interaction with others.

People with ASDs often engage in repetitive or stereotypical patterns of behavior. These include repetitive or specific ways of moving their body: finger flicking, hand flapping, and rocking back and forth. They may also want to insist that other people around them to do or say things in a particular way. Although many individuals with autism are sensitive to sensory input, some of them are quite interested in the sight, feel, sound, taste, or smell of things or people (Bernier and Gerdt, 2010). Sadly, some of them also engage in self-injurious behavior that can result in bruising, bleeding, or tissue damage (Webber, 2002).

Leo Kanner first introduced the concept of autism in his seminal 1943 paper (Wing and Potter, 2002), but until late the 1980s, autism was considered to be a rare condition. However, since the late 1990s, this view has totally changed. Recent studies have reported a progressive trend in the prevalence of autism (Baron-Cohen et al. 2009; Davis and Dimmond, 2010; Fombonne, 2003, 2005). However, this recent increasing trend cannot be directly attributed to an increase in the incidence of autism (Fombonne, 2003). There are several other factors that might influence the increase in incidence and prevalence of autism, such as changes in diagnostic criteria, difference in methods used in studies, increasing awareness, and development of specialized services. However, it is also possible that a true increase of incidence of autism has been observed (Ritvo, 2006; Wing and Potter, 2002).

Many studies have tried to explore the causes of autism. Unfortunately, the etiology of these conditions is still unknown. A variety of causes have been proposed, as there are different disorders in the spectrum of autism. Past studies have mainly focused on the domains of genetics, biology, neurology, environmental causes, and pregnancy (Yapke, 2003). Some researchers also focus on the causes of autism as gastrointestinal (GI) difficulties, because many individuals with ASDs have GI problems (Yapke, 2003). Some studies describe an underlying susceptibility of autism that can be triggered by environmental conditions. Environmental factors can also impact people during the prenatal and antenatal period. The areas of influence studied include infections, vaccinations, allergies, toxins, and antibiotics (Yapke, 2003).

ASDs are life-long disorders and they affect all activities of daily living. Although there is no known cure for these disabilities, there are many ways to compensate for their difficulties. However, if their symptoms are severe in nature and have too many associated disabilities, such as hearing and visual impairments, it is worth trying to educate both the individual and their

family and/or service provider on appropriate behavior and self-care (Wing, 2001). If a child with autism is very young, perhaps under three years of age, then they are eligible for an early intervention program; for children over three years of age, pre-school and school programs are available (Davis and Dimmond, 2010). Some people with mild autism symptoms can even complete higher studies. However, in most cases, they need help in organizing their lives. For instance, a child going to school may need a personal time-table, written instructions, or maybe even a special way of teaching (Wing, 2001). Despite many possible problems, the main goal of family members and professionals is to provide them a quality life through education and training (Hansen and Roger, 2013). It is evident that education, vocation, and community and family support play a vital role in adaptation and a positive outcome.

Professional support is often required for people with autism to establish more control in their lives. At the stage of diagnosis, professionals need to help parents understand the importance of high-quality intervention for their child and provide them specific referral to intervention sources. Professionals need to consider parents' emotions and help them cope with their children's diagnosis with ASDs. They also need to provide parents written information and help them find the best services for their children (Hansen and Rogers, 2013).

It is important for parents, caregivers and/or teachers to see the world through the eyes of people with autism (Thompson, 2007). Autobiographies and firsthand narration of individuals with autism provide a unique window into their experiences. Lawson, identified as a person with autism, describes his lack of understanding and control over his environmental outcomes. He states, "In order to cope with my incapability, I often try to manipulate my environment and others who share it. For instance, I might feel comfortable to sit in a particular seat, eat from a particular plate, and walk outside only with someone"(Lawson, 2001, p. 20). He also talks about

monotropism, that is, difficulties of coping with change (Lawson, 2001). He further states his difficulties with change in routine, expectation, instruction, daily schedule, and movement of attention (Lawson, 2001).

Grandin (1992) wrote that when she was a child, establishing verbal communication was extremely difficult for her. She found screaming was her only way of communication. Williams (1994 b) stated that she was often able to understand words, sentences, even contexts, without grasping the significance of a spoken message. She also experienced that the rhythm of walking while talking helped her to structure her thoughts. Some of them also reported that they did not feel the need for a relationship, loneliness, or sexual desire in the same way that non-autism individuals do (Grandin, 1995; Sinclair, 1992). People with autism experience time and place differently than people without autism. They state that transition between activities; changes of routine, waiting, and other time-related activities can cause discomfort (Olney, 2000; Williams, 1992 a).

People with autism often have sensory integration difficulties, so they see their world in a very different way. The response mechanism in their brains often works in a different way in processing senses such as touch, smell, hearing, taste, and sight (Sensory Problem and Autism, n.d.). Donnas' (1994) visual sense was limited, so she used her sense of touch by pounding, slapping, or tracking to establish boundaries between her and objects. Different individuals use different strategies to reduce sensory stimulation; for example, Grandin (1995) and many other people with autism used glasses to reduce visual stimulation.

It is known that autism has a major impact on family life. Fujiura, Jarbrink and Knapp (1994) stated that family members play a key role in providing care to people with disability.

Costs to families may include loss of employment, less leisure and recreation time, and economic hardship (Järbrink, Fombonne, & Knapp, 2003). Studies have indicated that coping in parents is determined by the symptoms of autism, their special need, and other psychological factors (Bernson, 2006; Hastings, 2003; Konstantareas, & Papageorgiou, 2006). Dobson and Middleton (1998) estimated that the cost of raising up a child with autism is three times higher than for a child without this disability.

Some studies focus on understanding what it is like to be a parent of a child with autism. The lived experiences of parents who have a child with autism can be very different from those of any other family. Having a child with autism shapes their parenting role and the world they live in (Roberta, 2010). Their experience can be characterized in several ways: parents enjoy less freedom, have limited social contacts, and go through a restricted and repetitive way of life (Cashin, 2004). Parents with a child with autism mostly may feel stigmatized, particularly when their children are more aggressive than passive. Consequently, many families isolate themselves from social contacts, due to their children's disruptive and antisocial behaviors (Gray, 1993). In a phenomenological Canadian study, parents describe their isolation as "living in a world of our own" (Hoogsteen and Woodgate, 2013). They also feel that their suffering is not recognized by society and that their community values a child with autism less than other children (Gray, 1993).

2.2 Transition: Concept, Types, and Goal

The concept of transition has been discussed in literature from different perspectives: developmental, situational, health-illness, and organizational (Schumacher & Meleis 1994). Developmental transition refers to an experience that happens during an individual's life cycle,

such as becoming an adult. Situational transitions are concerned with various professional or educational roles in management positions. Health-illness transition refers to the responses of individuals in an illness-related context (Kralik, Kate, & Loon, 2005), such as myocardial infarction, HIV infection, advanced cancer, and chronic illness.

Transition experiences are delineated in two ways: vertical and horizontal (Stoner, 2007). Vertical transitions are close to the concept of developmental transition, which all adults experience in their life. Vertical transitions include yearly grade change, high school to vocational post-secondary education, and school to adult life. Vertical transitions have received most of the focus in the academic literature (Rosenkotter, Whaley, Hains, & Pierce, 2001). On the other hand, horizontal transition refers to a situation that people experience in their usual life on a daily, weekly or monthly basis. Horizontal transitions are individual-specific and not as predictable as vertical transitions (Polloway, Patton, & Serna, 2001). Horizontal transitions include transitions between familiar activities and unusual situations. Example of horizontal transition are shifting to a new activity in a class, visiting a doctor, or meeting a new person.

Arnett (2007) termed this transitional phase as "emerging adulthood", referring to the age range from a person's late teen years to their mid-20s. He argues that emerging adulthood is an age of instability, possibilities, and identity formation. During this stage, adolescents become more self-dependent and explore various aspects of life (Arnett, 2000), and parents acknowledge their child as an adult and allow them to enjoy full autonomy.

The majority of the people in this transition continue to live at home, continuously negotiating their changing roles and relationships with family members. At the same time, they also expand their world outside the house towards a larger society (Jackson & Rodriguez-Tome,

1993). Sociological and cultural perspectives also focus on completing education, entering the workforce, becoming independent, getting married, and becoming a parent. During adolescence, young people shift away from parental control and become more interested in their peer group. If an individual's role is not clearly defined, they may be confused during this transition (Sebald, 1992). The young individual does not know, in a specific situation, whether they should act as a child or as an adult. Uncertainty in their social role can sometimes be stressful and cause anxiety and depression (McGee & McCoy, 1981). However, the range and influences of social environments differ from one individual to another. Such individual differences may result from several influential factors: parental guidance, personality characteristics, and cultural practices (Jackson and Rodriguez-Tome, 1993).

Young people in the United States go through the transition to adulthood from their own personal, individual, perspectives, such as making their own decisions, becoming financially independent, and taking responsibility for their own lives (Arnett, 2003). During the transitional phase, they experience a variety of issues: accessing post-secondary education, finding employment, engaging in the community, and developing personal and social relationships (Hendricks & Wehman, 2009). Transition to adulthood can also include leaving a residential school, leaving a long-term hospital accommodation, experiencing a significant life event, or moving out of the family home.

According to Viner (2008), transition is not simply a transfer from one facility to another, thus it should additionally include a goal-oriented system of care, geared toward greater self-determination and considering the medical, psychological, and educational needs of the young person. The goal of transition should include social skills, communication skills, and vocational skills. A successful transition is said to have been achieved when the feeling of distress is removed

and a sense of wellbeing is experienced through effective change events (Schumacher & Meleis, 1994). "Quality of life" is often overlooked, including relationships and leisure activities. Community integration should also be an important goal for people with autism, as this would help reduce inappropriate behavior and increase safety skills (Hendricks and Wehman, 2009).

2.3 Experience and Process of Transition

Generally, a person goes through several mental and emotional states during transition. Stress and emotional distress, frustration, anxiety insecurity, depression, and loneliness are likely to occur during transitions (Christman et al., 1988; Shea, Adamczak & Flanagan, 1987; Tierney, Grant, Cherrstrom and Morris, 1990). Support from family members, parents, and friends have a great deal of impact on transition (Battles, 1988). Lack of support, on the other hand, leads to feeling of powerlessness, confusion, and frustration during transition (Christman et al., 1988; Fishbein, 1992). Disagreement among family members can happen during transition, but agreement and commencement contribute to successful transition (Patsdaughter & Killien, 1990). Integration with the broader community is also a good strategy for healthy transitions (Meleis, 1987; Robinson & Pinkney, 1992). A wider socio-cultural environment also shapes transition experience. For instance, lack of paternity leave and inflexible work hours impedes the transition to fatherhood (Battles, 1988).

People with autism can experience normal physical growth, but their mental and social growth is impeded by their condition. Generally, they have difficulty coping with any change or transition, because they can't face the challenge of processing all of the information in a new situation, understanding what the expectations are, and knowing how to respond appropriately. They face enough difficulties already in social interactions, challenges in communication, and their tendencies to engage in repetitive behavior (Symptoms, 2014). Goals for an individual with

ASD should focus on individual skills and be functional in nature (Iovannone, Dunlap, Huber, & Kincaid, 2003). Problematic transitions can have a negative impact on an individual's academic and social life (Adreon & Stella, 2001). Hendricks and Wehman (2009) suggest that people with autism should be given a range of options to choose from for their best wellbeing.

Researchers suggest that the best way to make an effective transition for children with autism is to plan an effective co-ordination between professionals and families, where parent-professional interactions become an educational experience (Stoner, Angell, House and Bock, 2007). A recent Scottish survey identified a transition process as poorly managed when 95% of people with autism aged 15-25 felt they needed help in transition planning, but half of them did not receive any support (Reid, MacBean and Charles, 2009). Successful transition happens when an effective working alliance is made between staff and parents, where the staff values the person's history and devotes their energy to teamwork (Clegg, Osbeck, and Sheard 2001). Stoner et al. (2007) proposes to assist parents in developing a transition plan, as they constantly deal with their children's transition issues. There is no disagreement that parental involvement enhances benefit; however, studies found that parents are not effectively included in educational decisions and transition planning (Turnbull, Erwin, & Soodak, 2006).

2.4 Major Transition Issues:

2.4.1 Education

Like other students, people with ASDs have to meet the common goals of education: acquiring skills for living independently and becoming socially responsible (Kavale & Forness, 1999). Although many individuals with ASDs are capable of achieving a university level

education, they require academic and social support for a successful transition (Glennon, 2001). Students with autism can enroll in schools and colleges and socialize with other students. Lindsay (2007) argues that inclusion is a process of mainstreaming that has been established as a human right.

Studies indicate that educational achievement is lower for those with ASDs, when compared to their typically developing peers (USDOE, 2008). According to a classroom teachers' report, they are 5 years behind in mathematics and 4 years behind in reading (Myles & Simpson, 1998). Students with a diagnosis of autism often lag behind the expected milestones in an educational curriculum and need Individualized Education Programs (IEP), where students get individual assistance in their learning (Griswold, et al., 2002). Special educators in schools design strategies for students with autism to overcome challenges so that these students can achieve their educational goals and become independent. Teachers help them in building self-confidence, self-motivation, and social competence (Roberts, 2010). Students also get assistance from special educators in learning time management, attaining a stable environment, becoming organized, establishing a daily routine, and reinforcing adaptive behavior (Zager & Feinman, 2012). However, studies have also shown that many teachers feel that they do not have enough training to deal with children with ASDs (Batten et al., 2006). Parents also express their concern that some teachers attribute misbehavior of children with autism to their emotions or interpret this misbehavior as challenging authority (Myles & Southwick, 2005).

Leaving high school is an important transitional phase. In the school, collaborative programs are developed to support children with ASDs. The team ideally includes parents, classroom teachers, special educators, teacher assistants, a speech language pathologist, a consultant, an educational psychologist, and the student themselves. This team must work

together to meet the unique needs and abilities of the individual student (Saskatchewan Education, 1999). When exiting high school, youth with ASDs can face barriers that prevent them from meeting their needs in various ways. According to Howlin, Goode, Hutton, and Rutter (2004) people with ASDs face prolonged waiting lists and a lack of adult services that could help them achieve maximum independence. Taylor and Seltzer (2010) argue that improvement of autism symptoms significantly slows down when youth exit high school.

2.4.2 Employment

Employment has economic value and that creates a feeling that people with autism are valuable to society and have potential to contribute in the workplace. They are often very sincere and pay close attention to details. However, Gerhardt and Lanier (2011) found that the vast majority of adults on the spectrum are unemployed or do not have access to appropriate services. Data show that only 15% of adults with ASDs in the UK have paid employment (DOH, 2007). Many of them show high competency at repetitive and logical tasks such as data entry and IT (DOH, 2007). However, a large proportion of them are employed below their level of academic qualification, because of poor social skills and lack of self-management capacity (Wing, 2001). Some of them need special support to get and retain a job. On the other hand, many of them cannot work in open employment. They require sheltered employment where they can work in supervised settings with specially trained staff (Wing, 2001). It is also important that their managers and co-workers are trained in communicating with people with autism, because many people on the spectrum have difficulties working in a team. They may not understand typical jokes, gestures, facial expressions, and tone of voice (Davis and Dimmond, 2010). However, a large number of people with ASDs have no form of occupation and spend time in sedentary activities such as watching TV and videos and engaging in repetitive behavior (Wing, 2001).

2.4.3 Independent Living

During transition to adulthood, children typically move out from their parents' house to attend college or join the workforce. There are both positive and negative aspects of this shift. Leaving home gives them more opportunity to access program-based services, develop a better social life, and engage in age-appropriate living. On the other hand, lack of communication with service staff, loneliness, and decreased quality of care can make out-of-home life more challenging (Krauss, Seltzer, & Jacobson, 2005). Women with autism, when they live in institutional settings, are at higher risk of abuse than any other population, because some of them cannot even speak to defend themselves. They may not even know if a crime has been committed against them (Davis and Dimmond, 2010). Moving away from the family can be very difficult for some children with autism. Studies have found that parents prefer their children to stay at home rather than move out, because in some cases, appropriate alternatives are not available (Seltzer & Krauss, 1994). Studies show that 60% of children with ASDs in the US cannot move out during the transition to adulthood phase (Krauss, Seltzer, & Jacobson, 2005). They also found that individuals with autism had worsening maladaptive behaviors associated with moving out of their parental home.

2.4.4 Relationships

People with autism experience considerable discomfort in building and maintaining interpersonal relationships and have difficulty coping with emotionally stressful situations (Wing, 2001). Stress can arise during the death of a relative, a divorce in the family, or relationship breakdowns. They are less capable of maintaining contact, sharing emotions and developing intimacy with others. Some of them choose to stay isolated, while others desire to establish relationships. Because of their reduced control over their emotions, they can easily become

depressed, frustrated, or angry. Due to their lack of social skills and difficulties in managing emotions, they often fail to find friends and lovers (Henault, 2006). Their past negative experiences, such as rejection or bullying, may lead them to choose isolation, which has a negative impact on their self-esteem (Henault, 2006).

Individuals with autism face difficulties in expressing their sexuality. Sexuality includes emotions, values, behavior, relationship, and self-image (Koller, 2000). Transition to adulthood can be uncomfortable for people with autism and their caregivers. Studies found that adolescents with autism tend to have inappropriate sexual behaviors that are consistent with the nature of their disorder (Stokes & Kaur, 2005). Children with autism also face problems during puberty and adolescence. At this stage, adolescents with autism, particularly boys, may develop serious problems concerning their sexual growth. Consequently, they may suffer from mental retardation and depression (Christophe Grilberg, 1984), especially if they don't have access to appropriate training and educational resources (Koller, 2000). There should be support from the family, residential care providers, and health service professionals to skillfully manage the transitional physical changes that occur during this development phase (Laberg, 1984).

2.5 Gaps in Transitional Service in Saskatchewan

As the prevalence of autism continues to grow, the demands for effective services are also on the rise. The main focus of this study is on the issues of transition services in Saskatchewan. A review was conducted by the Ministry of Health of Saskatchewan (2012) to assess the existing needs of people with ASDs and to improve the quality of existing programs (Loutzenhiser & Sluth, 2012). According to the review report, adults with ASDs in Saskatchewan face challenges mainly in three areas: obtaining a stable income, finding suitable housing, and accessing assisted-living services. The committee found that half of adults with ASDs in Saskatchewan are

unemployed. Additionally, 83.3% live with their parents, and 8.3% live in group homes. Parents and service providers have suggested that more support is needed in the areas of life skills training, programming on companionship, community networking, accommodation with living services, and recreational support.

2.6 Strategies for Effective Transition Services

Every individual living with autism has unique symptoms; their needs are highly diversified. Due to their dependency and vulnerability, they require various supports to secure a healthy quality of life. A number of provincial ministries, including the Ministries of Health, Advanced Education, Social Services, and Economy are involved in supporting people with ASDs through funding and programs. Studies have identified several ways to improve the quality of transitional services. A good transition process should include: identifying a young person's needs, structuring transition, as a flexible process, towards adult services, providing services in a coordinated manner, and involving caregivers and families in the planning process (Colver et al., 2013). Parents of children with ASDs have identified other issues that require attention: services for emerging adults are not friendly, pediatric institutions leave them before they are emotionally ready for transition, and dependable relationships with new service staff are sometimes problematic (Amari, 2011). Reviewing current literature, Gerhardt and Lanier (2011) found that a large number of adults with autism in the US do not have access to appropriate services. Additionally, transition programs lack service co-ordination. Likewise, Tailor and Seltzer (2010) claim that the current service system is not capable of addressing the transitional needs of youth with ASDs. To improve service quality, Davis (2003) proposes increasing funding and reinforcing knowledge dissemination.

Some researchers recommend establishing a system of care for people with autism and their families (Burkhardt, 2012, p-2). "System of care" refers to community-based services that are coordinated, comprehensive, culturally acceptable, and family-focused (Brown, 2010). The ASDs community has three distinct groups 1) families of people with autism, 2) providers of service to persons with ASDs and, 3) the persons with ASDs themselves. Building communities may contribute to increased understanding of the challenges regarding autism intervention (Burkhardt, 2012).

A survey conducted in Virginia highlights some recommendations from parents about how to improve services for children with autism. The recommendations include: (a) improving the quality, quantity, accessibility, and availability of service; (b) educating and training people with autism; (c) increasing funding for service, training staff, and research; and (d) creating appropriate school placements (Dymond, Gilson & Myran, 2007). Likewise, another study consolidates the following recommendations for a successful transition strategy: (a) transitions should be child-centered; (b) there should be effective communication between school and home; and (c) preparation for the transition should include the child's input (Stoner et al., 2007). Dymond et al. (2007) talk about program deliveries that sadly assume a "one size fits all" approach, and advocate for provision of individualized services. Studies suggest that professionals need to have an educated understanding about each child's transitional issues, understand what works best for each child, prepare detailed transition plans, and facilitate effective communication between home and school (Stoner et al, 2007). Tobin (2012) suggests that communicating a willingness to support facilitates a positive transition, even if there is a lack of resources for service delivery. Batten et al. (2006) and Maras and Averling (2006) states that communication is the key for community support. The findings of Tobin (2012) and his colleagues indicate that some parents

believe inclusion to be an unrealistic strategy. Parents have also experienced stress in school selection, statutory assessments, and preparation for transition.

In this chapter, we have discussed how the issues of transition for adolescent children with autism has been addressed in the contemporary studies. Some of them explored knowledge and information through the experiences of parents and family members. Some other studies have also focused on broad areas of transitions such as education, employment, relationship and independent living. All the studies aimed at improving the management of transition and quality of life for people with autism. In the next chapter, we will enter the methodology of the current qualitative study. We will introduce grounded study methodology and how the methodology is applied to this study.

CHAPTER THREE

METHODOLOGY

This chapter discusses the grounded theory research methodology that has been used in this study. It also presents how the ethical approval and consent of the participants were achieved. This discussion is then followed by a brief presentation on research methods that includes: sampling strategy, inclusion and exclusion criteria, identification of participants, data collection, data saturation, data analysis, flexibility, and scientific rigor.

3.1 Research Design

The design of the research follows the grounded theory methodology, which is based on a naturalistic model of inquiry. In 1967, Barney Glaser and Anselm Strauss introduced the grounded theory approach in their book "The Discovery of Grounded Theory". According to Glaser and Strauss (1967) grounded theory is an inductive methodology that allows researchers to generate theories from the perspective of participants as they listen closely to the ideas of participants. When using the grounded theory approach, researchers identify key explanatory concepts and their relationships to a given topic (Glaser, 1978). Over time, grounded theory has been used in different disciplines, and researchers have enriched grounded theory through their contributions. Creswell (2005) has argued that there are mainly three dominant types of grounded theory designs: systematic design, emerging design, and constructivist design. Systemic design in grounded theory is widely used in educational research which an emphasis on data analysis steps, development of logical paradigms, or a visual presentation of the theory. Emerging design (Glaser, 1992) argues that the focus is on connecting categories and not simply on describing

them. Finally, the researcher builds a theory and discusses the relationship among categories (Creswell, 2005)

In this study, I will use the constructivist grounded theory, which has been adopted from Glaser and Strauss' (1967) methodological strategies, but with a new epistemology. Constructivists have assumed a pragmatic and relativist epistemology that considers how the researcher's and research participants' values influence interpretation. One of the assumptions made under the constructivist approach is that data and theories are co-constructed by the researchers through their interactions with study participants, rather than discovered solely by researchers (Charmaz, 2011). The constructivist approach acknowledges multiple realities, also suggesting that generating knowledge is a co-creative act between the researcher and the participants, and that it "aims toward interpretive understandings of subjects' meanings" (Charmaz, 2000). The grounded theory methodology facilitates a process of developing inductive theories that are grounded in systematically gathered and analyzed data. The research process under grounded theory has different phases, which include: identifying research problems, developing research questions, data collection, data coding, analysis, and theory development (Richard & Morse, 2013).

Grounded theory is particularly useful in areas where not much research has been done previously. As discussed in this study's review of the pertinent literature, there is very little known about the process, experience, and transitional needs of people with autism. Therefore, this study will be a beneficial to the canon of knowledge. It is important to understand human behavior, relationships, and organizational contexts. The goal of grounded theory is to build theory from data, use pre-determined hypotheses, study real problems, and is explicitly interpretive (Charmaz,

2003). Over time, grounded theory has come to occupy an important place in the methodological complement of qualitative studies.

Constructivist grounded theory would benefit the current study because we are aiming to understand the process of transitional experience. We acknowledge both the experience of people with autism and the professional people working for them. The discovery of knowledge about transitional needs in this study is a co-creation of the participants and the researcher.

3.2 Ethical Approval and Consent Process

An ethical approval for this study was obtained from the Behavioral Research Ethics Board at the University of Saskatchewan (See appendix A). After getting approval from the Ethics Committee, potential participants were contacted. The ethics application included procedures for contacting participants and explained in detail that participation was completely voluntary and that participants' identities would not be revealed to the researchers. Ethical standards were maintained throughout the study by careful attention to issues of recruitment, written consent, confidentiality, anonymity, potential vulnerability, and sensitivity. According to the guidelines of the ethics board, the original data was stored in a locked filing cabinet, and are accessible only to the committee members and the researcher. Also, the researcher uploaded data electronically to his cabinet on the university server. They will be kept in a locked cabinet at the University of Saskatchewan for at least five years, in keeping with University of Saskatchewan policy, and will be destroyed after that time.

Consent forms (Appendix B) were stored separately from the research data. The researcher used a written letter of consent from all participants. The participants read the consent form; upon agreement, they signed the form before beginning the interview. The participant and the researcher signed two copies of the consent forms and a copy was left with the participant.

The form contained detailed explanation about their participation, the goal of the research, what is expected from participants, expected time of the interview, etc. It was also explained, prior to the interview that the participant can withdraw for any reason, at any time, without any explanation. If the participant withdrew, their given data was deleted. It was ensured that the interview location was quiet and secure; it was a place where people could engage in a free and confidential conversation. After the first interview, the researcher asked the participants if they were willing to participate in a second interview. In every interview, the researcher obtained a written consent from the participants.

3.3 Sampling Strategy

I started the interviews based on initial sampling. Initial sampling in grounded theory is a starting point, which considers sampling people, their settings, and the larger context before entering the field (Charmaz, 2007). Parents of people with mild to severe autism and professionals working in the field were interviewed for this study. After initial data collection and analysis, theoretical sampling procedure was employed. Theoretical sampling, guided by emerging theory, is concerned with where to sample next (Corbin and Strauss, 1998). According to Charmaz (2007), theoretical sampling helps to elaborate and refine emerging categories, and to develop the properties of categories until no new properties emerge. Theoretical sampling procedure was also employed in making the decision for second interviewing. After analysis of the first round of interviews, the researcher found some potential interviewees who could contribute more on emerging categories and themes. Those participants were contacted for the second interview.

3.4 Research Participants and Inclusion Criteria

Family members and professionals from service-providing organizations are mainly concerned about the wellbeing of people with autism. Although both groups might have different

experiences about helping people with autism, they work for a common goal. As people with autism have difficulties in communication, it was anticipated that listening to both groups would be helpful for the researcher to understand transitional experiences in a comprehensive manner. Therefore, it was decided that people from both groups will be recruited for the study. The inclusion criteria for the first group was that the parents or the caregivers of the people with autism live in Saskatoon or the surrounding rural areas. As we are interested in looking at their transition to adulthood, the age range for the participants with autism would be 13 to 25. The inclusion criteria for the second group was that the individuals were involved in service delivery and policy formulation in Saskatchewan: therapists, residential caregivers, autism program supervisors, managers, researchers, or government officials.

3.5 Identification of Participants

Since I worked for Autism Service Saskatoon, I had access to organizations working in this field in Saskatoon. To recruit participants, I approached professionals who were working in service-providing organizations. Particularly, I contacted professionals working for Autism Service Saskatoon and Cosmo Industries. I sent them formal invitation letters (Appendix C) through email, which listed the goals and objectives of the research, confidentiality issues, time commitment for the interview, contact information of the researcher, and explanation of how the participants will benefit from this study.

As this information was disseminated, interested participants began to contact the researcher. Also, professionals responsible in managing programs in Autism Service helped to find prospective participants for both groups: a) people with autism and their caregivers; and b) professionals involved in autism policy formulation, program management, and services delivery.

Managers of Autism Service also mailed invitation letters to prospective participants. In addition, the researcher asked the participants to assist in finding other participants.

Some interviewees willingly passed the researcher's contact information to prospective participants. Appointments were made through email or over the telephone prior to the interviews, according to the participants' convenience. In most cases, parents invited the researcher to their residence for the interview. Interviews with professionals were taken in their offices. In these interviews, both parents jointly participated, responded to the questions, and supplemented each other's answers. As they have gone through the same experiences, a joint interview seemed quite helpful.

3.6 Benefits for Participants

This research is potentially beneficial to the participants in many ways. For example, participants may become more aware of their rights, gaining knowledge about available services. This research could be considered a pioneering study in Saskatchewan - generating theory on the transitional experience and process of people with autism. This study will also be useful in formulating effective policies and programs by government and nongovernment organizations in the field of autism. In its application, this study's aim is to make a contribution to both the research literature and the ground practice of evaluating existing programs. For instance, Autism Service Saskatoon has expressed the view that the study findings will help them understand their program relevance and use.

3.7 Data Collection

An important aim of any study is to obtain detailed, complete, and accurate data. Rich data must reflect subject's opinions, feelings, meanings, and intentions, taking into consideration

the context and structure of their lives (Charmaz, 2007). Grounded theory allows researchers to collect data using one or a combination of methods. For instance, a researcher may conduct in-depth interviews, ethnography, oral life history, and document analysis (Corbin & Strauss, 2008). In this research, data has been collected from field notes, intensive interviews, and information from reports and records.

Face-to-face intensive interviews were conducted following seven guided questions. The method of intensive interviewing fits with grounded theory methods; both are open-ended, direct, and flexible. Intensive interviews allow respondents to describe experiences in detail. The researcher is free to request more details, ask about the participant's feelings, and come back to earlier points (Charmaz, 2007). As recommended in grounded theory, field notes were taken during the entire research process to provide description of the participant's environment, processes occurring in their environment, and anything else that the participant found disconcerting (Charmaz, 2007). Field notes were taken during and after the interviews and were analyzed throughout the research process.

Artinian, Cone and Giske (2009) states that the use of audio recording in interviews helps novice researchers in identifying missing ideas and key concepts. A cell phone was used to record the interviews. After each session, data was transferred to the researcher's personal laptop. These recordings helped identify the need for second interviews with two participants to get more insight or detailed explanation on their previous statements. Based on the first interview and analysis, the researcher also developed new questions for second interviews. Second-interviewing allowed the researcher to establish trust with the participant, get more insight on the issue, and confirm emerging themes.

Data was analyzed immediately after each interview. Some common themes began to emerge after the first few interviews. The researchers felt that more information was needed to get clarify these themes. In certain cases, participants were re-contacted and requests were made for second-interviews.

3.8 Data Saturation

No direct formula can determine the sample size in qualitative research (Morse & Richards, 2002). The process of simultaneous data collection and analysis allows the researcher to understand when saturation of categories has been reached. According to the guidelines of grounded theory, the researcher can stop gathering data when categories are saturated. Categories become saturated when data no longer contributes new theoretical insights, and no new properties reveal theoretical categories (Charmaz, 2007). In this study, I stopped interviews when I became satisfied that new data are no longer producing new theoretical insights, nor were new properties of the pattern emerging.

3.9 Data Analysis

As grounded theory dictates, data collection and data analysis were done simultaneously throughout the research process (Charmaz, 2000). Transcriptions were made immediately after each interview, and the transcripts were reviewed repeatedly to find meaning and understand themes. Data was coded in three stages: initial, focused, and theoretical (Charmaz, 2007). Initial coding examined data line-by-line and searched for concepts, categories and patterns. To ensure that findings were grounded in the data, the codes used the participants' language, or "in-vivo coding". At the second stage, focused coding was conducted. At this level of coding, the researcher gave some analytical sense of category, as Glaser (1978) argues: focus coding is more

directed, selective, and conceptual than line-by-line coding. Once initial and focused coding were completed, I began to understand the emerging themes in this data.

With each additional interview, more themes and critical areas continued to emerge. At this stage, I used separate pages to draw relationships within the data, to bring the data under common criteria, and to identify emerging themes. According to Glaser (1992), this kind of analysis leads to theoretical coding. As Charmz (2007) says, theoretical coding is a sophisticated level of coding that follows the code that the researcher selected during focused coding. Theoretical code exposes possible relationships between categories that the researcher developed in his focused coding. As data was analyzed after each interview, and after a couple of interviews from both groups, I looked back on guided questions and research objectives to confirm whether or not I was on the right track.

3.10 Reflexivity of Research

Qualitative research is subjective, acknowledging that the researcher and participants both have a reciprocal influence in the research process (Rallis & Rosssman, 2003). Cutcliffe (2000) argues that it is important for the researcher to acknowledge his or her position and prior experiences and their potential impact on the study. It is imperative that the researcher is aware of their personal beliefs and positions, which may have an influence on the research. As a researcher, I came to this study with previous experience from working with people with autism. I worked in group homes in Saskatoon where male and female adults lived. In my work I supported them in their daily living. I had to deal with both day-to-day transitions, and those that occurred over a longer term. I acknowledge that my personal experience had the potential to impact my research, processes, and outcomes in this study.

Working with people with autism led me to select this research topic. I was aware of the nature and severity of autism and the sacrifices of the families. My colleagues taught me some strategies that became part of the theory of this study. After developing this theory, I know that transition strategies can be more effective if we follow all the steps. During the analysis phase, it became evident that I was constantly comparing my prior experience with the data that I got from the interviews. I think that comparison process enriched the analysis. Most of the interviewees in this study were unknown to me. I personally knew only one female participant, who lives in the group home where I work. Also, two professionals whom I interviewed were my colleagues.

I learned a lot of transition management techniques throughout the research that I did not know before. As I listened to the participants' stories, I began to understand how transition techniques are employed in divergent situations. I discovered some families who have member with autism whom I did not know before, although I know them for a long time. I became a bit surprised and realized that people with autism are not very visible. Families feel stigmatized and most of the time they chose to live in isolation. I visited their homes and talked with their parents and siblings. It gave me an impression that families are sacrificing a lot for the people with autism. I was new to performing qualitative research using the grounded theory, so it took some time to become comfortable with this methodology. For example, I needed to assess my interview techniques and to identify strategies to improve the process to identify the participants' main concerns and their attempts to resolve their issues.

3.11 Factors That Influence This Study

The study was influenced by the experiences of those who were willing to participate in the study. People who did not willingly participate might describe their transition experiences differently. In addition, participants were located through professionals and organizations that

involved in providing services to people with autism. This study may not address the experiences of people with autism who are not closely in touch with these service-providing organizations.

3.12 Scientific Rigor

Rigor will be achieved in this study by following Charmaz's (2007) guidelines for the evaluation of grounded theory studies: credibility, originality, resonance, and usefulness. Tobin and Begley (2004) define rigor as the manner in which integrity, competence and quality of research process are ensured. These criteria will be applied throughout the research process.

Several factors are considered to ensure credibility. For instance, in-depth data has been gathered from participants with first-hand knowledge of these transitions. Also, systemic comparisons have been made between observations and categories; strong logical links have been made between gathered data, arguments, and analysis; and data has been collected until saturation has been reached.

This study can also claim originality because the categories are fresh and emerge from the data collected in the study. They offer new insights in the issue of transitional needs. As the study provides ideas and recommendations on existing services provided in Saskatchewan, it has the merit to challenge current ideas, concepts, and practices. Further, originality will be achieved through producing new knowledge and insights on the gaps of transitional needs of people with ASDs in Saskatchewan.

The criteria of resonance has been established in the research process through verification of respondents' interpretation. Resonance has been achieved in the study because the theory developed herein is totally based on the experience of people with autism, their caregivers, and

service providers. The study will make sense to the participants and provide deeper insights into their lives.

This research will fill gaps in the current literature. These observations of the study-participants will help make a better world for people with autism. It will facilitate better understanding of the transitional need for the people with autism in Saskatchewan. It is anticipated that identifying gaps in current services will help organizations to improve or modify their existing programs. Hopefully, this research will improve of the quality of life for the people with autism in Saskatchewan.

Grounded theory is systematic methodology that allows researchers constricting theory through the analysis of data. The researcher starts with questions and collects data, reviews the data collected, repeated ideas, concepts or elements become apparent, and are tagged with *codes*, which have been extracted from the data. We followed the same process in this study and finally came up with a theory of transition and gaps in transitional services for people with autism. The results of this study has been presented in detailed in the next chapter.

CHAPTER FOUR

RESULTS

This chapter begins with a brief description of the participants in this study. My aim is to understand their symptoms, diagnoses, and the severity of their condition. This is followed by a presentation on the theory of transition that has been developed in the study. This theory offers an explanation of the main concerns of transition for people with autism and their caregivers and how that transition is being resolved or processed. Lastly, it discusses the current situation on transition services and identifies areas to improve service quality.

4.1 Samples

Twelve interviews were conducted for this study. Ten people participated: five of them being parents and five being professionals who work with people with autism. Interviews were taken until saturation was reached. Parents were interviewed about the transitional experiences they and their children with autism experienced through life events. The people with autism ranged in age from 12 to 25 years. Two of them are male, and three are female. Their diagnoses included Autistic Disorder, Pervasive Development Disorder Not Otherwise Specified (PDD-NOS) and Asperger's Disorder (AD). The interviewed professionals were employed with the Ministry of Health, Autism Service Saskatoon, or were freelance consultants. There was some overlap between the two groups of participants. Two individuals who were interviewed as professionals also had a child each with autism. Another parent interviewee has been working as a professional in this field.

Table 1: Demographic information of participants with autism

Sl no.	Pseudonym	Age	Sex	Diagnosis	Residence
1	Jessica	25	Female	Asperger's Disorder	Lives in a group home
2	Lisa	13	Female	PDD-NOS	Lives with parent
3	John	26	Male	Autism	Lives with parent
4	Francis	23	Male	Autism	Lives with parent
5	Brooklyn	17	Female	Autism	Lives with parent

All participants with autism in this study have unique symptoms. I will use pseudonyms in this thesis to keep these individual participants anonymous. One parent described his 25 year-old daughter with autism who currently lives in a residential facility: "When Jessica was born, till 4 or 5, she had a lot of medical issues. She never spoke, no communication whatsoever for the longest of times, she was very slow at things. Also, Jessica was hearing impaired. Presently, she has 45% hearing loss". He also said, "Jessica is a master of lip reading; when you whisper in her ear, it does not matter if she has a hearing aid or not, she knows what you are saying".

Lisa's mom was worried about her behavior. She said, "Lisa has a severe behavior. She was very aggressive and self-injurious. Now, that is not the main issue. There is a communication barrier. She doesn't talk very much". Lisa is passive in conversation. Her mom says, "This is not

new. Since she was small, she could not have a back and forth conversation properly. It's very little. Sometimes she'll ask, "How are you?", "Where is mom?", and "Where is dad?"

John, who needs one-to-one help, stays at home. His mom talked about him. "When he became an adult, he quit liking other people. He just wanted to be in our little group and he doesn't like strangers. He doesn't like crowd anymore and he wouldn't go anywhere. So he became very isolated."

Francis's mother described his disruptive behavior. "The challenges for him have a lot to do with his behavior. He might get overly upset at the snap of a finger. He can be smiling one minute - and the next minute, he might be yelling at someone's face. He doesn't understand boundaries. He doesn't understand that he is not supposed to be doing that and it takes some time to calm him down or to get him to act in an appropriate way. He is still learning how he is supposed to act. He is much more like that at home than when he is out in the community".

Brooklyn also has a severe behavioral problem. She had Autism when she was 2 years old. She can read; write; do multiplications in 2, 3, 4, 5 and 10; and add and subtract. She has lot of skills, but her safety issues stop her from being independent. Her mom talked about her. "It's pretty severe. She is going to need to live in a group home and be in sheltered work. She can talk, but it's 'demand speech'. She tells me what she wants rather than conversing". Brooklyn has no concept of danger and needs to be supervised around the clock. Her mom also said, "So you need the knife drawer to be locked and scissors put away. If there is a bath, she will put the plug in and then, she will put water so that it overflows and she puts things down the toilet. If the door is open, she will run away".

From this introduction to the five participants, we can see that they all are highly dependent on family members and others. Their symptoms are diversified, and vary from low to high. They have some common areas of impairment, but every individual with autism is unique.

The parents we studied discussed this diversity of symptoms of people with autism. Brooklyn's mom said, "We need to always remember that people with autism take longer to process things, so we should not get mad at them". Jessica's dad said, "You have to work with people with autism. It's such an enormous spectrum because if you have met only a few, you won't know. It ranges from people you need to take care of for everything, to the most intelligent people in the world".

4.2 Transition: The Main Concern

Transition refers to the change or passage from one state or stage to another. The participants in this study described transition in two ways: small changes that happened in day to day life on a regular basis, and changes in life-stages which refer to big events. One participant said, "Her transitioning was with almost everything in her life - change with people, change to the environment, change of rules, changing of seasons, changing of workers, changing of teachers in her school, changes of how people are reacting at her". Another parent said, "Transitioning is one of those words they use a lot in autism because so many people have a problem with it". An interviewee who works for people with autism said, "Working with teenagers is quite different, so working through the piece. It's a transition not just for the individual who has autism, but also for the families". One therapist, in explaining this situation, said, "They want to follow everything in a specific way. For instance, after getting up from bed, they need to brush teeth and then have breakfast. They have some specific things such as taking off their jacket and shoes. They are used to following a routine. If the routine changes, they become frustrated". Another interviewee said,

"The big picture with transitioning these kids are to be very slow and they have difficulties in communication. Their patience is very limited".

Participants shared different experiences of transitions. My interviews revealed that the experience of transition is not just an issue for the individual with autism. As people with autism are dependent on others, it becomes an issue for family members; they are highly involved with this transition. Jessica's mom said, "We put her in a group home and that was a three-year transition". She also said, "I think, for her, a big transition is going to be when her education is finished. She spends most of her day at school". Lisa's dad said, "We moved here and it took one year to settle down because of behavioral issues. The city changed and the school changed. I had close relatives and family friends, so coming here was different because she had a new school and a new teacher and it affected her". Jessica's mom talked about the transition experience while moving to a new house, "We got her into a building stage of the house. We brought her here every night to talk about how she is going to sleep in her own bedroom. That went on for 4 or 5 months in the house that was being built". A program manager said, "And there are also many transitions going on. I mean any of us can deal with death in the family, we can deal with moving, we have coping skills, some of us cope better than others".

Children with autism pass through the same process of transition to adulthood as any other child without autism, but for children with autism the process is far different. During the teenage years, some of them become physically mature but their mental development may be far behind. Becoming an adult, particularly for the girls, may make them more dependent on others and raise worry for their safety. Lisa's mom expressed her worry as Lisa was growing. She said, "Yes, she is already going through puberty. Actually, for a few months, when she was going through puberty, she was very bipolar. One minute she was crying and the next minute she was happy.

Now, I think she is settled down. She is 13 but she looks 15. Physically, she's turning into a woman, but mentally, she is not at that age". She also said, "One of my concerns is her personal care, because she can't do things on her own and needs help. Another thing is a safety issue. As a girl, she doesn't know what's safe and what's not. It can be dangerous, I want her to be safe".

Transition to adulthood is a challenge for the whole family. Sometimes family members are confused on how to deal with the issues of transitions. One interviewee with a professional background said, "A lot of parents are afraid. They don't know how their child will deal with it". This may be their first experience with autism. And, even if they have some experience, autism is unique. In severe cases, needs constant, one-to-one care. One care giver said, "This is a very broad topic because there's so much to think about. A lot of things aren't communicated enough. Once they reach adulthood, everything changes. There's no smooth transition, because they are left in the dark. And we're trying to fix that, but it's a long road". Another professional said, "I would say working with teenagers is quite different, so working through the piece, it's a transition for the individual who has autism but it's also a transition for the families."

4.3 Resistance to Change

Changes often happen in our life; we adjust our routines accordingly. Throughout our discussion on transition issues, it was revealed that people with autism do not like change. They like everything to happen according to a routine. Changes in routine make them frustrated, which is manifested in their behavior. The main concern of transition of the people with autism was "resistance to change".

Participants described the problem with transition as, "He is really resistant to change", and "she does not like surprises". Jessica's parents explained the problems of transitions, "We are

going for a movie, fifteen minutes, let's go! Those things don't work. They just don't work in her world". Resistance to change can be found more in teenagers as one professional said, "But it's more difficult as they become adults because typical teenagers resist being told what to do. So they will resist, too, and it gets harder. You need consistent support".

The effect of adolescent transition differs for each individual with autism. One professional said, "There are challenges for sure. Even though they are adjusted to a work place, throughout life there are changes. Also, there is a daily transition of going from home to work. I mean, that's a transition most of us don't even notice. If we drive five minutes in the car, most of us have to have coffee to do whatever we need to do to get our mind frame into work. For them, that transition doesn't come easy. For example, if they come home from work, sometimes you'll see increase in behavior for a while as they're adjusting back home".

They are used to a routine; if it changes, they become frustrated. Lisa's mom said, "She has built a routine and you cannot change her routine because she doesn't like change". If school is off for one or two days, they do not like it. One interviewee said, "If they see a new situation or a new person, it is very challenging for them". A consultant said, "As long as we carried out our normal routine and structure, he was fine". Jessica's dad had the same experience. He said, "She lived with us all the time. Her routine was: going to bed for a couple of hours, and then waking up and getting out of the bed. If you tried to change anything, everything would get wrecked or destroyed".

Any change that they are not used to or do not like makes them frustrated. People with autism express their frustration in their own unique ways. One parent mentioned that they have limited patience. "If you were to throw something new to her, she would get frustrated. Then she

would outbreak her frustration, by hitting and breaking things, and self-abuse or become aggressive towards workers”. John’s mom describes the experience, “She has three consistent workers at her workplace. But, when they change that, it’s a disaster. It’s almost like all those new people have to get them to win her over first. It sounds really mean, but that is how her world is. I don’t know if that’s her coping mechanism, but they need to win her over first”. Jessica’s mom shared her experience, “Many times, we would wake up to the stove being turned on or to the house being flooded out. It’s all to gain attention. They are smart in their own ways”.

4.4 Managing Transition

Family members and caregivers support people with autism in many, if not all, aspects of their lives. They have discovered, through this experience, their own methods and techniques to manage the challenges of transition. Participants resolved their main concern, the problem of resistance to transition, by using the basic social process of “managing transitions”. They defined this as, “We all manage them to get there” and “You have to deal with the situation”. Managing transition, according to one participant, meant: “...if you do it in a systematic manner, it will work well”.

Managing transition can be broken into several sub-process concepts: "making a plan", "introducing change gradually", "communicating effectively", "working in a team", "making a supportive community", and "retaining support staff". Sub-process is also affected by the individual's particular autism diagnosis, their level of severity along the autism spectrum, their age, and the amount of support they receive from others.

4.4.1 Make a Collective Plan

Planning is the first and most important function of managing transitions. Planning is made according to the individual's capacity for coping with change. Planning helps caregivers to choose the best strategies for transition, organizes resources, and systematically introduces them to change. All interviewees emphasize the importance of planning. One professional said, "Some of them will get through transitions, but some of them need it planned very well. If too many things happen at the same time, you will definitely see a change in behavior". Francis's mom described the importance of planning, "His transitioning to almost everything in life is difficult, but if you plan and take time, then it is okay. He needs a lot of planning ahead to do something. For instance, if we were to go on a holiday, you need to start with it about a month before or more by explaining him with books and other stuff about what we are going to do". Jessica's dad talked about planning for her daughter. "When we make a plan, that is more likely to be work. Ninety percent of the time, my wife does a good planning because she works in a school and knows what they do". People who are involved in supporting the person they know the best about the situation of individual. It works well when they make a plan collectively to support transition.

4.4.2 Introduce Change Gradually

As people with autism cannot deal many things at a time, we need to introduce new things gradually to help them cope with change. If we attempt to change home and school simultaneously, it might not work for them. One professional talked about his experience, "We cannot suddenly give them admission and ask them to go to school". He also added, "For some, this is more challenging when transition goes from elementary to high school. Many teens are in this group. We start way before - from June". Lisa's mom said about the same experience, "If they go from one class to another, for instance, they are in grade one and will go to grade two, we do

not directly put them in grade two, we introduce them to the students and teachers first". A professional said, "Sometimes, we'll bring them in for one hour. First day, one hour and second day, two hours. This way, we introduce the change to them slowly. If we do not do this, they will face behavioral problems". Similarly another professional said, "Transitions were planned by the schools. They had their EAs go with them to the work placement where they would go after school. They start up to two years before the end of school to visit the workplace and the EAs spend more time with them in the workplace to get them adjusted. Then, they gradually back off so that the person is already used to the place and people and have gotten adjusted to the new environment". Francis's mom shared her experience, "Their patience is very limited, so you are there for a short time and then you have to go. Next time, a little longer, and next, a little more. That's how you transition him".

Jessica's dad talked about his daughter's transition to a group home, which took a long time, "That was a 3 year transition. When we first put her into a group home, there was a bedroom ready for her right away. We would take her there for a couple of hours on Saturday. She would be with the workers there, getting used to it. Then, she would stay there overnight. The next thing was to take her there for 2 nights. Then my son was living in a home and we built it into her thoughts that it was time for him to move out, and it was also time for her to move out. She could visit him whenever. It was a duplex with four guys. She is moving in with three other people, she is the fourth. So seeing him, she too would graduate into it. You just cannot take them and throw them in there; it is never going to work".

John's mom also stated the same experience about her son, who was getting prepared for transition to a group home. She said, "So now, we are going to be transitioning to the new autism house. We have people coming here three days a week, and they stay overnight so he can get used

to working with other people and not just me. It is going very well. He really likes Anna and now we have introduced Dana and it seems to be going better. Then, as we get closer to him moving there, we think we are going to bring the group home staff here for a whole month before he goes there, and I will disappear to see if that helps. But he will have a hard time in a new environment. If it is not done, we have asked that John have his own TV room and chair. If he has that, we think he will be very happy because he doesn't like other people around. Hopefully it happens. They are promising us that it will, but we have to wait and see what happens".

4.4.3 Communicate Effectively

Communication difficulty is one of the most common characteristics of people with autism. So it is important to find strategies for effective communication for them. Parents and caregivers follow different techniques for effective communication such as telling them repeatedly, sharing them social stories, showing pictures, and doing role play. Lisa's mom said, "So when you transition from one subject to another, or from one activity to another, you need lots of preparation. You can write social stories, you can do all sorts of things to prepare". Francis's mom said, "We have to tell them before several times. If we can explain through pictures, that is more effective for them than talking to them". One therapist said, "Some of them don't understand while some of them do. In that situation, we tell them a social story and demonstrate through pictures. For instance, we tell stories to explain their body is changing. We try to make them understand".

Another professional shared his experience, "When we find a client is close to 16, we make a social story. Based on the client, we make a story for easy understanding. If they have a less understanding level, we then do video modeling or we find similar items on YouTube". Several techniques are used to communicate effectively based on what suits the individuals. For

instance, an autism-support professional said, “A grown up girl frequently takes off her clothes. But at this age, it is not good to take off clothing openly and she does not understand that. In that case, we use role play and social story techniques to make her understand”.

Lisa’s mom talked about social stories, “If we are going to do something new, I write a social story and tell her what is going to happen. Then, we have a board every day for what we are going to do that day. She will go over it. If you want to put things in, then you do, but you still give good preparations, especially if it’s things that she doesn’t like. She is very flexible on things that she does like, where some children aren’t even flexible with what they really want or like. If I suddenly say, 'We are going to your grandparents,' she would be thrilled, but if it was somewhere else, she didn’t want to go, then I would have to make preparations."

Based on individual needs, different strategies are employed to make them understand. For example, one professional said, “One of my clients is like this. She likes to kiss and hug everybody, whether they are her parents or strangers from the street. It becomes a problem when a teenager is kissing everybody on the streets”. Then they write a story to show her whom she can hug and kiss and they also do a role-play and show her pictures.

4.4.4 Work as a Team

Families living with people with autism need support to make their daily lives proceed smoothly. Support can come from extended family members, family friends, neighbors, community organizations, therapists, professionals, and organizations involved with providing service. All of these stakeholders need to work in a team to make their support effective. Coordination and communication between team members is important, because that helps to maintain consistency of services.

John's mom said, "I need help so that I can work 5 days a week, which is not available. He gets his monthly money that we live on, because I quit my full time job when I brought him home. I am working 15 hours a week, but you can't live on that". John's mom also talked about how she is receiving help from other family members. "I have my niece who has lots of experience. We wouldn't survive without her, and I have my two other boys. My youngest boy still lives at home, because he helps me. My other son is married; he doesn't have much time. I need help for everything. If I didn't have my niece, I would have jumped into the river. She moved back from Calgary to help us. She worked in Calgary with autism services".

Participants also recognize that co-ordination and teamwork is vital to smoothing out a transition. Jessica's dad talked about communication and teamwork. "If you do not work as a team and have very good communication, it will fail. Life on your part, if you are a caregiver, will be hell. If you do work together, everything will flow very well". Francis's mom said, "The workers themselves have to be a team. It's a challenge, because that didn't happen in the home a lot". John's mom said that in the group home, communication and teamwork were essential in managing the home in a productive manner. She said, "I would say teamwork and communication is number one, then consistency, which is to do things over and over. If a person leaves their shift, the next person has to know what is going on because you have a communication going on, so that there are no surprises." She also talked about flexibility, "And be flexible, because if you are going to be a person that is all about power, you are losing. Because they would win. You should be flexible in your tactics around it, and be patient. People who want to be too professional in trying to be with them usually hurt them. You need to be yourself; people need to understand that they are at that age". Another professional talked about co-ordination between home and workplace. She said, "If they come home from work, sometimes you'll see an increase in behavior

for a while as they're adjusting back home". These professionals apply some strategies to deal with those difficulties. She said, "There is definitely a big difference between work and home in approach, so we need to have lots of communication between work and home, and lots of meetings dealing with different situations. You can't always be consistent between the two places, but if there is something you can do similarly, it always helps."

4.4.5 Make a Supportive Community

During the transition to adulthood, adolescents increasingly interact and socialize with the greater community. They experience a lot of barriers during their dealings with others. Physical and cognitive statuses are the main barriers to their communication with others. Due to a lack of information and awareness about autism, a lot of misconceptions are created which lead to a lack of communication. If the community becomes more knowledgeable about autism, then it will become easy for them to live in the community, because they would get a supportive environment. Some of them also need support from the community because they lack proper social behavior skills. Francis's mom said, "He might get overly upset at the snap of a finger; he can be smiling one minute and the next he might be yelling in someone's face. He doesn't understand the boundaries, he doesn't understand that he is not supposed to be doing that and it takes some time to calm him down or to get him to act in an appropriate way". Lisa's mom also said similarly, "She is still learning how she is supposed to act. She is much more like that at home than when she is out in the community, because I think when she gets home, she is much more relaxed. In the community, she tends to hold together a bit more and doesn't usually have tantrums. But I think, as time goes by, we have to figure out if that's going to be an issue". Francis's mom said, "Cognitively, he is not able to do something on his own, but physically he is able to do things like getting around in the community and engaging in community activities, doing basic things like

buying things at the store, or using money, going on a bus”. Sometimes, they need more training to be able to associate with others in the community. Francis’s mom also said, “I have 2 young men who work with him, and one of the young men takes him out on Saturday mornings. In the afternoon, the other young man takes him to recreational activities; they go mini-golfing or swimming. They are trying to integrate him more into the community in a more independent way”.

Increased awareness of autism is also needed at school and workplaces. One therapist said, "If their classmates understand, then it becomes easy; lots of parents do not send their kids to school due to bullying”. Jessica’s mom said, “All the time he’s asking or talking to classmates; he then becomes a victim of bullying. Lisa’s mom reported that, “Because other children do not understand autism, they insult children who have autism”. Other people think very negatively about people with autism and create a barrier that prevents them from associating with the community. One interviewee who works for the people with autism reported, “One day, one of my clients came to my house with his son, who has autism. My son, who is in grade six, told me that the boy was weird and he did not like the boy. When I started a conversation with my son, I found that he does not know anything about autism. He also told me teachers never discuss autism in the classrooms. Lisa’s mom expressed her concern and frustration regarding her daughter’s classmates, “One thing she go very close to people when she wanted to communicate with them. What I've seen is that when I'm walking with her, she'd run off and go very close to a classmate, and the classmate would move away. I felt really bad about this. I knew she liked them and wanted to talk to them, but other kids were not interested. She would invade their personal space. This was an issue I noticed. At this new school, everybody's very helpful, and she has dropped the habit of invading other's personal space. Now she does that very little”.

4.4.6 Retain Support Workers

People with autism usually get care from support staff through organizations. They like to deal with the same people. They feel uncomfortable when they see new people are coming to help them. John's mom said that changing the staff who support him can be a disaster. She said, "He has three consistent workers. But when they change that, it's a disaster. So, now he has got three workers who are really to stay and be in it, but they are constantly introducing him new people". Even changing the bus driver can be a problem. Jessica's parent talked about her experience, "Bus driver changes happened 10 times a year. She doesn't do well with changes in bus drivers because she needs to try and manipulate them".

A long-term relationship with the staff helps them smoothen their transition. John's mom talked about it, "I have a commitment from them this time that his day program is not changing, because he is big on building relationships. We worked hard to get those relationships built, because it's all on the people and they have started to come. For example, staff have been coming for 6 months; they have just been able to get him out of the house because he hasn't left the house very much in the last year. So that relationship is built and the girl who comes on Thursday will never be able to get him out, but they have an awesome day at home, and the girl who comes on Friday will be able to get him out".

Staff who have worked with people with ASDs for a long time become almost like a family member; they are someone whom parents can rely on. Jessica's dad talked about a long-term staffer. "Robert helped her transition into the group home. We had that consistency, always. We still have it, because Robert is still with us. It's like doing the puzzle one piece at a time, slowly. If we go to a family wedding, Robert comes with us. We always tell our daughter, you are bringing your date, and Robert's the date. Things go smoothly, because she knows Robert's

understanding, she knows our understanding. But if we lose Robert, we would be very sad. He is a very key worker. He is easy going and he knows her well”.

4.5 Summary of the Theory of “Managing Transitions”



Figure 1: The basic social process of managing transitions

Above is a visual illustration of the theory on managing transitions. As we can see in the diagram, transition can cause a lot of problems if it is not well managed. That happens because the patience and tolerance level of people with autism is low; they have less control of their emotions and a reduced capacity for understanding others’ feelings. If we don’t go through appropriate management techniques, we see that they often become physically and verbally abusive. They can become angry, violent, aggressive, and engage in self-injurious behavior. Also,

they can become fearful, start crying, or run away. All these reactions can also trigger other symptoms.

However, a well-managed transition will lead people with autism to cope with change. It will build their confidence so they will not get scared or get angry. It will help them feel relaxed and prevent them from reacting in a negative behavior. The theory proposes six strategies for managing transitions. The strategies are to make a plan, introduce change gradually, communicate effectively, work in a team, make supportive community, and retain staff. These are the common strategies that parents and caregivers in our study developed to manage the main concern of the study “resistance to change”. Transitions can be smooth and successful when the strategies mentioned above are applied in a comprehensive manner. For instance, if parents, caregivers, and service providing organizations do not work in a team, transition cannot happen smoothly.

Other contextual factors also influence transitions, which are shown in the diagram above: comorbidity, diagnosis and age; family, community, school and organizations; and institutional policies. Every individual with autism is unique; some have severe symptoms, others have mild symptoms, and some have comorbidity. How well a transition works would also depend on the individual's diagnosis and age. Furthermore, the surrounding environment, such as family, community, school and organizations, also has an influence on their transition. Having supportive family and community members is always helpful. Government and institutional policies also have an impact on transition. Particularly, access to funds, common facilities, and support staff depends on government and institution policies.

4.6 Understanding Autism Service and Gaps

The second objective of the study was to understand the gaps in the autism service available in Saskatoon. People with autism need services from organizations and professionals in every stage in their life. The organizations working in this field design programs according to their age and needs. After a person is diagnosed with autism, it is recommended that they get Applied Behavior Therapy (ABA) for 20-35 hours per week to help them with autism-related developmental disorders. One of the interviewees who works as a therapist said, "We assess the child first and see what they need by having a discussion with parents and teachers; then we make a plan and implement an intervention. We do one-to-one intervention". A professional said, "They need therapy, because at the beginning, they will have eye-contact problems and gross-motor limitations".

Programs through service organizations provide training, residential and recreation services. One professional said, "We have lots of social groups and programs for recreation. We have teenage groups where they learn how to interact with each other". Another professional said, "We do things like swimming, horse riding, and bowling. Also, there is an arrangement for music therapy and art therapy. After becoming an adult, they are supposed to live independently, so they usually move to a group home". Another interviewee who works as program manager said, "We also have a residential program and community living service delivery; they are for adults. We now have four programs. One of the homes has two programs. It's a group home upstairs and a supported-living apartment downstairs for higher-functioning people. And the other two homes have people with higher needs". There is also a vocational program in Regina that helps them acquire skills to get a job. A professional said, "There are also places for their assisted work. But they are not taking new people in that program".

Both the parents and professionals we studied were asked about needs and gaps in services. Most of them agreed that there is a gap in the autism service in Saskatoon, particularly for people who are transitioning to adulthood. One professional said, "We can't address the ongoing need. We all try to do a piece of it, but it doesn't work". From the conversation, seven themes regarding gaps in services have emerged. A summary of the participants' experience on gaps in autism service is presented below.

4.6.1 Need for More Programs

Parents recommend there should be more programs available for people who are transitioning to adulthood. One parent said, "For children between 12 and young adulthood, there is not a lot of programming available in the city. I would say there are no transitional programs available. There is nothing that teaches kids self-help skills or community living skills; there is nothing". Another parent said similarly, "Last summer, we enrolled him in a summer program. Once in a week, we took him to that program. He felt happy and enjoyed the program very much. But they are not offering those programs anymore". One mom who also works as a consultant said, "We don't have support from any service agencies; we hire people privately to work with him. The fellows that work with him are educational assistants working at some of the schools in town. We just hire people and train them to do what we want them to do".

Also there are gaps in the availability of trained professionals to help people with autism. One professional said, "If anyone wants to pay personally, they do not find a therapist. I have a client and I cannot give her one-to-one teaching because we do not have enough staff. Not having enough professionals is a gap". One parent demands to make therapy available at school. She said, "She is spending most of her time in school. We do therapy once a week, which is not enough. If she learned similar things at school, such as therapy, she would improve a lot".

4.6.2 Need for Individualized Programs

Programs for people with autism might not address an individual's unique needs, because a variety of diagnoses fall under the term of autism. For instance, Francis's mom said, "There hasn't been anything that really fits with him appropriately. He also has juvenile diabetes; we have to monitor diabetes as well, and that needs constant care, so it's a bit more complicated". John's mom said, "I think the service programs have to be really specific to what the child needs. You can't take kids who are functioning at the lower end of the spectrum and put them with kids who are functioning at the higher end and hope that you are going to achieve a good outcome". One couple who works as consultants said, "If my partner and I developed some kind of program, we still need people who can pay privately for that program. And at this point, it is hard to get people to commit to that". Autism stakeholders want government funding, so they can afford those programs. One participant who works in the field of autism said, "We are trying to get the government to commit to funding for those kinds of programs, but so far, we have come up pretty short in that regard".

4.6.3 Need for Trained Education Assistants (EA)

Children with autism participate in the same classes as other students. If they have learning difficulties, EAs assist them in school. EAs can effectively help them - if they get proper training in dealing with autism. One professional talked about the role of EAs, "I've seen a few of our existing residents finish High School. Transitions were planned by the schools. They had their EAs go with them to the work placement where they would go to, after school. They start up to two years before the end of school, visiting the workplace and the EAs spend more time with them at the workplace to get them adjusted and then they gradually back off so that the person is already used to the place and used to the people as the EA from the school decreases so they get

adjusted to the new environment”. Lisa’s mom said, “I think that the EAs don't have proper training and don't know how to handle them”. She also said, “At the beginning of middle school, I actually had issues with the Special Education teacher. I wanted a lot of things from her for my daughter”.

4.6.4 Need for More Agency Accountability

Organizations working for autism need to find appropriate monitoring strategies to keep the service quality up to the standard. John’s mom was devastated because her son was brought back home after having lots of conflicts with the residential care agency. She experienced that agencies have excessive power and they do not focus properly on their job. To express the agency's limitations, she said, "When my son was being mistreated by the residents, I didn't see any compassion or anybody stepping in, it was just meeting after meeting, and really nothing changed”. She said, “It didn't appear to want a change. It needs to be a strong watchdog. These agencies get too much power”. She also said, “People that fund these agencies told us they have no control over staffing or anything and I don't think this is the way they should operate”. Francis’s mom said that the agencies do not deal with families in a proper way. She said, “From my past experience, I find that there was absolutely no respect for the family, none! I didn't feel respected”. Parents suggest that there should be a watchdog to supervise agencies. Francis’s mom also said, "That's what needs to happen. They say all these standards are in place, but I don't think there are enough watch-dogs, I don't think that the people funding them are having enough power over these agencies.” They also want more control from funding agencies. John’s mom said, “How can people funding an agency that is supposed to be looking after these people continue funding when they know well that it's not happening”.

4.6.5 Need for Residential Facilities

The transition to residential care is an important phase for people with autism. It was revealed in this study that getting a residential placement is very time consuming for them. Sometimes they don't even get a suitable place to live. John's mom talked about her experience: "Everybody knows that the process is very slow and in my opinion, ineffective. Because if a family is in crisis, they need help right away. And that doesn't work, as all our systems take time. Some of these families need homes right away because they can't cope". One residential manager said, "We want to have time to build homes so we can make durable living places that won't collapse in a week. That long process can't be stopped, but it can be sped up". One professional talked about the long processing time for getting a place in a group home. She said, "There's no timeline, really, because what happens is, we have a list of people who would be interested in placement. But we have to put in a proposal for the government to get funding for a new home. And when we think we have the capacity to do that, we put in a proposal. We can attach their names into a proposal. The government will get back to us and say that they don't have enough funding. So we work with social workers and try to get people who are compatible and have enough funding. Once a proposal is approved, we have to send out letters. So it's a process that could take years". One professional said, "I mean, there are stories of abuse at nursing homes and there are lots of questions for the families. Sometimes, we have families that aren't sure they want to place their child in a home, but they realize the child is aging and they won't be able to care for them". One residential manager said, "There are a lot of people who need placement. I don't know how the government will take care of that".

4.6.6 Need for Vocational Training

Vocational training is to obtain and retain salaried employment in the general community upon graduation. Since people with autism have learning difficulties, vocational training can contribute to give them some specialized training that fits with individual situation. There is a lack of vocational training for people with autism in Saskatoon. One autism professional said, "If they were employed properly, they would do a very good job. There are not many programs to give them skills. There is a gap. So when they go to a group home, they don't have to do anything. They just go to Cosmo and spend time there. They did not develop those skills earlier. We need to create more opportunities for them. Then we can involve them in the community". Parents wanted vocational programs in Saskatoon which would address an individual's need for skill development. One interviewee said, "I think they are doing vocational program with ARC (Autism Resource Center) for people in Regina, it's specifically based on that person".

Francis's mom said similarly, "That to me seems reasonable. If you are looking at doing the vocational skills, it's about finding the aptitude of the person and then gearing that course towards people who have that aptitude. For example, if someone is good with numbers or patterns, they may be able to do a certain type of job or skill, and they can group those people in a certain type of job or skill set. But right now, they're not in a lot of division, they just lump everybody together and it's mostly recreational".

4.6.7 Need for More Funds and Trained Staff

Both the parents and professionals mentioned that there is a massive funding gap for autism programs in this province. One professional said, "The funding here is absolutely ludicrous, it's 7.5 million dollars we spent on autism. And that includes intervention services and respites. If you compare that to Manitoba, which has nearly the same population that we have, the

disparity in services is enormous. That's a big part of the issue". Brooklyn's mom talked about the shortage of staff for funding, "I think we do not have enough staff because there is not enough funding, which becomes crucial. For example, we have recreational programs, but we cannot offer that because there is a shortage of staff". Services are not available even when families are in a crisis situation. One program manager said, "For some families, there's not a lot of support in place, so it's really tiring for them. You might have a parent who is afraid of their child at a point because the child might now be bigger than the mother. If they become more aggressive, it's not a good situation, so families end up in crisis during those years". Even safety is compromised because of the lack in funding. One professional said, "Sometimes you need two staff members for one individual for safety. There's always funding issues to get this happening". It appears that there is more funding needed to address the needs. "There is a need and we try to address it with the resources we have, but we would just need a lot more funding and people".

4.6.8 Need to Review Policies

Some parents and professionals mentioned that some policies need to be changed for the well-being of people with autism. Since people with autism are less capable of making good decisions, there should be guidelines for them. Jessica's dad said, "There are human rights issues where workers say that people with ASDs should have the right to make their own decision. It should be very individualized per person, because my daughter is not capable of making a very good decision for her well-being". He gave an example, "We spent a lot of money fixing her teeth, and we asked workers to cut back on all the Coke that they gave her. They said she has a right to have what she wants. She doesn't know when to stop, so she will drink 10 Cokes if you give it to her every day. The next thing you know, she has no teeth, and all her teeth are starting to rot out. She has to have somebody give her little bit of guidelines or rules for her. It's the human rights

that says they have a right to make their own decisions, and she can't make that decision. If you give her a hundred dollars to buy clothes, I can guarantee you that she will spend the money on Coke and pudding. We are against that, we feel that we should have someone say about what she does". He also talked about the rules in the group home. "If they don't want to brush their teeth or brush their hair before they go to work, workers say that's their right. To me, that should never be negotiated. Some norms that they used to follow at home changed after transitioning to a group home". He also said, "For us as parents, watching how she has transitioned, there are a lot of devastating parts of it, because she had that routine down pat. When you transition her, there should be rules. This is what we do in the morning, we brush, eat and get ready. If you start doing those things in a pattern, they will get the hang of the pattern and won't miss that. There's a lot of room for improvement, because that's how we function to keep her going. He also added, "But if they are routines they will not fight; they expect that to go next. They just need structure in their life; they need a lot of prompting to keep that".

4.6.9 Need for Change in Funding Policy

Some interviewees want the government to give money directly to the families; they talked about this change in policy that has happened in other provinces. Francis's mom said, "The only way anything will change here in Saskatchewan is, if the government gives direct funding to the families. If you give money to families, they will spend it properly on services that is better for their kids". She also mentioned those programs as reactive. She said, "It's not really proactive but reactive. Right now, you basically get whatever is being offered by the few agencies that are present. But there are too many kids, and not enough space or programming, because of less staffing. I would definitely like to have more programs that are proactive, but again, who is going

to pay for it?" They think policy changes would benefit in different ways, such as a new program would be available and more professionals would move to Saskatchewan.

One professional similarly said, "I think you would see a dramatic increase in the services provided and also people coming from other provinces to provide service, because right here, we have a lack of services". Another said, "We need people everywhere - from speech therapists to behavior interventionists and occupational therapists desperately. But why would they come here, if there is no incentive to be able to do their work well. It would help people in rural areas as well, because they would be able to access service in their communities without the need to have everything spread out". They also think giving funds directly to families would increase services in rural areas. One said, "Right now, if you are in Tisdale, you are not going to get the same services as you get if you're in Saskatoon, because the services don't exist. But potentially it could happen, if there were people willing to band together and get those services".

One professional said, "In British Columbia, they found that more service providers were available, more qualified people moved to the province, and more people in the province will be qualified. Because the government has changed the guidelines that can provide those services. You have to have a certain amount of accreditation, a set of guidelines that says these are approved services".

Study participants think direct funding will increase the accessibility of programs for families. Francis's mom said, "If parents had the opportunity to have that money towards putting their child in something on a consistent basis, they would be more likely to access those programs. But right now, we hear often, "Oh, it's the costs". "I can only afford so much". One professional said, "A lot of these kids don't get access because they don't have funding for it". One parent

added to the issue, “Say you get X amount of dollars towards your child’s program, you can use that money at a center that is providing service, but you get to choose what your child goes into. When you have access to that money, more services pop up”. She also added, “Right now, there is no incentive to provide more services because there is no money available. People aren’t willing to shell out”.

In summary we can say that this study proposes a theory on managing transitions and also identified the areas of gaps in providing services for young adults in Saskatchewan. As we know, people with autism have a neurological condition that impend them to cope any type of change. Absence of well-managed transitions causes manifestation of unacceptable behavior of people with autism. That puts the families and caregivers in a vulnerable situation. The theory of managing transitions provides clear strategies that we have discussed in this chapter, which caregivers and family members can follow. Later we have also identified some gaps that are important to ensure the services are provided in an effective and efficient manner. Service providing organizations, researcher and government policies can take those gaps in consideration. The result of this study would contribute to bettering transitions for people with Autism.

CHAPTER FIVE

DISCUSSION

This chapter begins with a discussion of studies that were conducted on transition issues for people with autism. It gives an opportunity to know how other studies addressed transition issues. It also highlights studies on the needs of service for people with autism. The chapter concludes by discussing the implications of the study.

5.1 Experiences and Processes of Transition

Participants in this study defined the issue of transition as changes that happen in their life, which ranges from changes in day-to-day life to different stages of their life. The experience of transition includes changes to the environment, rules, seasons of the year, service workers, school or home location, becoming an adult, moving to residential care, and so on. Some other studies introduced the concept of vertical and horizontal transitions (Kagan, 1992, Polloway et al., 2001) to explain types of transitions. Vertical transitions denote big changes in life stages such as changing schools or moving into residential care. In terms of students, vertical transitions could be viewed as movement from school to higher education or from one year to the next. Horizontal transitions could encompass movement from an institution to work or home, or within the institution from a formal learning setting to an informal one. Horizontal transitions refer to movements of people from one situation to another, which occur on a regular basis, which all individuals face in different ways, as part of daily life. These are not predictable, like vertical transitions (Polloway et al., 2001). Horizontal transitions include: going to a doctor's chamber, going to school, or visiting a family friend. Literature in transition has been focused much on vertical transitions (Rosenkotter et al., 2001).

People with autism are not comfortable with transitions; changes in routine are problematic for them. That change can be anything: meeting new people, coming back home from school or just little changes in their daily routine. These simple changes can make them frustrated, which may lead them to cry, run away, or engage in inappropriate or self-injurious behavior. They are resistant to change, and during transitions, their behavioral problems increased. Adreon & Stella (2001) conducted a study with school children who had Asperger's Syndrome, they reported similarly to our study, that people with autism are uncomfortable with unstructured activities such as bus rides, changes of classes, and unstructured time before and after school. They also found that during these times, their sensory stimuli and noise level increased.

In this study, we suggest that in order to make a successful transition, collaboration and communication among service organizations and family is a must. A study on managing the transition process from high school to college and beyond by Geller & Greenberg (2010) makes recommendations for a successful transition. They suggest that an educational transition must be developed collaboratively, involving the full participation of the student, his or her family, and the appropriate school personnel. They also recommend that other members in the student's life, such as therapists, coaches, agency service representatives, and medical professionals, should contribute by sharing their knowledge to the development of this plan. In our study, we saw that when parents were involved with teachers at the school, the transitions worked better. They also proposed the planning must begin by age 14; by 16, the elements of the plan must be in place. In addition, they identified some areas, which should include in transition planning: continued development of necessary social skills, as well as development of life skills. These would include money management, hygiene, housekeeping, maintenance of health, personal organizing, traveling, and driving. They also recommended sex education, instruction about managing related

personal behavior in adult settings, pre-vocational activities, understanding the work search process, and appropriate support for post-high school education, college, technical education, apprenticeship, or other training.

It was identified in our study that the main concern of the people with autism is “resistance to change”. A well-managed transition is needed to address this concern, and will help people with autism to feel relaxed and prevent them from engaging in socially unacceptable behaviors. In our managing transition theory, we suggested six strategies of effective transition: (a) make a plan; (b) introduce change gradually; (c) communicate effectively; (d) work in a team; (e) make supportive community; and (f) retain support staff. Stoner et al. (2007) investigated the perspectives and concerns of parents of young children with ASD related to transitions. Six major themes emerged from their study: (a) parents considered child-centered transitions to be effective, (b) communication between school and home was a vital link for successful transitions, (c) preparation for transitions began with an understanding of the child, (d) parents identified barriers to successful transitions, (e) parents understood different types of transitions but focused on horizontal transitions, and (f) parents identified effective transitions. Both the studies have some similarities: discussion of individualized plans, communication between service providers, and emphasis of parent experiences.

Stoner et al. (2007) study focused on parents’ understanding of transitions. Similarly, in their study, parents’ responses revealed numerous meanings for the word “transitions”; parents recognized the layers of transitions throughout their child’s life. Stoner et al. found that parents’ perspectives regarding transition are complex and usually filtered through the needs and characteristics of their children. In their study, all parents responded by focusing on horizontal transitions: transitions between home and school, teachers and classes on a daily basis, and being

home to go to doctors' appointments. Some parents spoke of vertical transitions: yearly transitions between teachers, transitions to new schools, and future transitions to high school.

In my study, we found that every individual with autism is unique and they have diversified needs. It is imperative to know an individual's ability level and use that to make a proactive plan. Themes emerging from Stoner et al. (2007) study also emphasize individualized plans. They recommend that education professionals need to: (a) gain specific knowledge of each child's transition issues; (b) understand what works best for each child; (c) plan for daily and yearly transitions in advance; (d) facilitate open and honest communication between home and school; and (e) realize that as children age, parents become more willing to discuss and plan for the transition from school to adult life.

In our study, parents and professionals focused on shared planning, trained staff, and coordination among agencies. Our findings are close to Hoole, Couteur and McConachie (2011) study, which also developed strategies for effective transitions. They defined transition as a process with flexibility in moving to adult services. They suggest that the transition should be centered on the young person's needs and identify their wishes and aspirations. They added that transition depends on readiness, fully engagement of both child and adult services in planning, and sharing information while taking account of a young person's wishes for confidentiality. To improve transition service, they recommend (a) having staff trained specifically in meeting the needs of people with ASD; (b) working closely with other agencies to ensure that the health plan is incorporated into a young person's broader transition plan for young adult life; and (c) involving parents and caregivers where the young person is reliant on their support. Most of their findings are similar to our study.

Our study found that planning is the most important component for successful transition. Families and agencies both play an important role for successful transitions and there needs to be effective communication between them. Dawn and Hendricks (2009) came up with some recommendations for effective service delivery, and some of their findings are similar to our study. They emphasized the importance of planning for transitions and that it needs to begin when students are between 10 to 13 years old. They suggest that successful transitions require thorough preparation and implementation. They say that continual involvement, planning, and careful co-ordination between the school and key community agencies are essential to improving outcomes through the transition process.

5.2 Services for People with Autism

As the prevalence of autism continues to rise, parents of older teenagers and young adults are seeking assistance for the transition to adulthood. Participants in our study noted some issues that indicate gaps in services that need close attention. Our study states that people with autism are facing challenges with employment, social relationships, and daily living. In addition, adults with ASDs must also face challenges in education and housing. Depending on the severity of symptoms, required resources and services may range from residential care, vocational training, or social-skills development. Similarly, Thomas Pelt (2008) noted, “Adults face inequity that comes from a lack of understanding about autism. Although autism is receiving substantial attention, adult autism and related issues have been neglected”.

In my study, the participants pointed out a lack in trained professionals and unavailability of services for adults with ASDs. They also recommended an increase in co-ordination and system efficiency. Some of our participants similarly suggested a correlation between an increase in co-ordination among agencies and effectiveness of services. A review was conducted by

Loutzenhiser and Sault (2012) on the Regina Health region to identify gaps in autism services. Similarly, they found lacks in areas such as service co-ordination and alignment, comprehensive case workers, information for families regarding services, systems and training, ASD-specific training for professionals, services for adults with ASDs over the age of 21, and quantity of services. In their report, they recommended an emphasis on the development of social and pragmatic language skills. Both studies revealed that many adults are facing difficulties in schools, communities, and workplaces due to their lack of communication skills.

In this study, we did not cover access to service related issues. A study conducted by Thomas et al. (2007), based on a community sample of families in North Carolina, reported that access to care is limited for racial and ethnic minority families with low parental education who live in metropolitan areas, and who do not follow a major treatment approach. These disparities in service associated with race, residence, and education point to the need to develop policy, practice, and family-level interventions that can address barriers to services for children with ASD.

Participants in this study also mentioned that they need financial, communal, and professional support. Similarly, a study conducted by Brown (2005) identified areas where people with disabilities need their communities to provide financial support, an accommodating school system, and good relationships with social workers, responsive professionals, and comprehensive medical care.

Participants in this study also brought up the issue of low funding for people with autism. Dudley and Herbert (2014) reported, according to the 2010-2011 statistic, that the average funding for an individual with ASD in Saskatchewan is the lowest, among six other provinces in Canada; funding for autism services in Saskatchewan is only half of what people in Alberta

receive. Autism is expensive, particularly for those with a severe condition. For some individuals, lifelong support is needed. If there is a gap in funding, families may struggle, and it will lead to no-care and substandard-care scenarios.

Our participants also questioned the current model of funding. One professional who is also a parent of children with autism proposed providing funding directly to families of people with autism, rather than funding service organizations. Funding to organizations creates supply-driven services. Organizations receive funds from government agencies and they design, develop, and deliver programs and services for people with autism. Families have to choose services from limited sources because they do not have any control on resources.

Some of our interviewees reported a shortage of skilled professionals and limited programs, since the available programs do not meet an individual's unique demand. Limited organizations and services provide few opportunities for families to choose appropriate services. If the government funded the families directly, it would create a demand for service. Then families will have stronger voice in the service-providing marketplace. Demand-driven models facilitate diverse services, which would create individualized services and help retain skilled staff in this province. Our government might consider other models of funding to increase the efficiency of funding and address the need for services.

In this study, we found that there many dissatisfactions and a great deal of needs to address. Similarly, a study conducted in Ontario (2008), noted that there is no consistent government policy regarding the need for support and services for adults with ASDs. They also commented that families and caregivers are not getting the help needed to plan for sustainable services and support. They criticized the current piecemeal approach and urged for a collaborative and comprehensive program. They also found insufficiencies in vocational employment,

education, social and recreational services, supported living options, and professional support. These included psychological, medical, and psychiatric assistance, dental care, person-centered planning, case co-ordination, respite care, crisis supports, and legal assistance.

5.3 Implications

5.3.1 Implications for Parents and Caregivers

Any transition is challenging for people with autism, because they are resistant to change. Parents and caregivers attempt to create smooth and successful transitions for them. The results of this study add a unique insight into the transitional experiences for those who have children with autism and those who are working for people with autism. The grounded theory developed by this qualitative research on managing transition provides an opportunity for the caregivers to practice the strategies of transition and verify if the theory can be generalized or is transferable to their own situation. A greater understanding of these experiences may aid parents and caregivers to assist successful transitions so that people with autism will be able to cope with a new situation in a more effective manner and their adverse behavior be reduced.

Every individual with autism is unique, however there are lot of similarities in their areas of difficulties and pattern of behavior. Our theory of managing transitions gives six broad strategies of managing transition. Parents or caregivers can adopt these strategies into their own situation. For instance, one strategy is to introduce change gradually. One participant explained how they used this strategy in their own situation. The experiences brought forth in this study can assist in increasing knowledge and understanding of parents and caregivers on managing transition.

5.3.2 Implications for Policy

The conversations in this study have identified gaps in services which can be categorized in different segments, such as management, funding, and availability of services. This study will provide thoughtful information, both for the people who formulate policies at the provincial governmental level and for organizations that are providing services for people with autism. The knowledge and information compiled in this thesis can be used by service providing organizations to evaluate their programs. Some interviewees identified gaps in services and also proposed suggestions for better co-ordination regarding their transitional needs. For instance, parents said that staff change can be very difficult for people with autism. They also talked about the suitability of transition programs, trained staff, and long waits for residency. Organizations can take these points into account in order to better aid people with autism and their families. The respondents also came up with some recommendations for policy change. For instance, one respondent proposed funding families rather than organizations, making transition services available, encouraging effective transition programs, and reducing existing gaps in transitional needs. Other issues also need to be considered, such as the issue of need for vocational training, response to the need of a residence in an overwhelming situation, ensuring the rights of individuals, effectiveness, and suitability of transition services.

5.3.3 Implications of Transition Research

This exploratory study suggests a grounded theory on transitional process for people with autism. It proposes strategies on how to make a successful transition. Although autism is a broad spectrum, this study will help researchers understand transitional strategies. Furthermore, this study can provide useful insights for future research into transitional needs. It is also important to continue researching service gaps in the area of transitional needs. This study provides

information to the prospective researcher, identifying certain gaps in service. Based on the findings in this study, additional research is required to develop further insights into transitions. For example, future research can investigate how transitions are experienced by the whole family unit, including siblings, the effect on the parents' career(s), and also studying the unique experiences of those from other cultures.

5.4 Closing Thoughts

Autism is a lifelong condition where individuals need help from family members and others to continue their day-to-day living. The prevalence of autism is rising; it is almost one percent of the population. The etiology of the condition is still unknown and there is no known cure. So, it is imperative to focus on symptom-management for autism. Families are primarily responsible for people with autism, and their support is huge. Having a child with autism makes a family more likely to become poor and isolated. It is very hard for people who have not gone through the same experience to understand the struggles these families have to face. It became evident over the course of this study that families need more help from their community and service institutions. This study was an opportunity to listen to family members and caregivers of people with autism. I hope that the theory on managing transitions can successfully contribute to autism management. Not much study has been done on autism management, access to services, and evaluation of service policies. In the near future, I want to see more studies on autism. It was also revealed in this study that there is a gap in autism services. To further develop autism services, we need to increase facilities to provide training in life skills, recruit more trained staff, and provide more individualized programs.

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Appendices

6.1 Appendix A: Behavioral Research Ethics, Certificate of Approval



UNIVERSITY OF
SASKATCHEWAN

Behavioural Research Ethics

Certificate of Approval

PRINCIPAL INVESTIGATOR
Nazeem Muhajarine

DEPARTMENT
Community Health and Epidemiology

BEH#
14-31

INSTITUTION(S) WHERE RESEARCH WILL BE CONDUCTED
Saskatoon
Saskatchewan, Canada

Regina
Saskatchewan, Canada

STUDENT RESEARCHER(S)
Ezajul Hoque Chowdhury

FUNDER(S)
INTERNALLY FUNDED

TITLE
A Grounded Theory Study of Transitional Needs of People with Autism during the Stages of Emerging Adulthood, in Saskatchewan

ORIGINAL REVIEW DATE
11-Feb-2014

APPROVAL ON
13-Mar-2014

APPROVAL OF:
Application for Behavioural Research
Ethics Review

EXPIRY DATE

Invitation Letter for Research Participant
Consent for Participation in an Interview
Interview Guide

Full Board Meeting ☐

Delegated Review ☒

CERTIFICATION

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.usask.ca/research/ethics_review/

Beth Bilson, Chair
University of Saskatchewan
Behavioural Research Ethics Board

Please send all correspondence to:

Research Ethics Office
University of Saskatchewan
Box 5000 RPO University, 1602-110 Gymnasium Place
Saskatoon SK S7N 4J8
Telephone: (306) 966-2975 Fax: (306) 966-2069

6.2 Appendix B: Consent for Participation in Interview

As a requirement of doing a thesis for MSc degree, Ezajul Hoque Chowdhury, a student of Community Health and Epidemiology at the University of Saskatchewan will be interviewing me. I understand that the research is designed to gather information about people with autism. The purpose of this study is to gain an insider's perspective of the experience and process of transition for the people with autism during the stage of emerging adulthood.

I am willing to volunteer to participate in the interview. I will be one of approximately 12 people being interviewed for this research. I understand that I will not be paid for my participation. I do not have to participate at all, or, even if I agree now, I can terminate my participation at any time without prejudice. I also do not have to answer individual questions if I don't feel comfortable.

I understand that the discussion in the interview will be interesting and thought-provoking. The questionnaire has 5-7 questions and the interview will last approximately one hour. Notes will be written during the interview. An audio tape of the interview and subsequent dialogue will be made. If I don't want to be taped, I will not be able to participate in the study.

I understand that the researcher will not identify me by name in any reports using information obtained from this interview, and that my confidentiality as a participant in this study will remain secure. Subsequent uses of records and data will be subject to standard data use policies which protect the anonymity of individuals and institutions. Except the researcher and the principal investigator, no one will have access to raw notes or transcripts. I understand that the researcher may have to interview me more than once to get more information in some areas of the topic. The re-interview may take about half hour or less.

I understand that this research study has been reviewed and approved by the Research Ethics Boards of the University of Saskatchewan. I have read and understood the explanation provided to me. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study.

If I have any questions or concerns, I can contact the principal investigator Professor Nazeem Muhajarine at the University of Saskatchewan.

I have been given a copy of this consent form.

My Name :----- My Signature----- Date-----

-

Investigator's name: Ezajul Hoque Chowdhury: Signature----- Date-----

-

For further information, please contact:

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6.3 Appendix C: Invitation Letter for Research Participant

Dear Sir/Madam

You are being invited to participate in a research study for a Master's thesis. The research will be conducted between the months of March and December 2014. The purpose of this study is to gain an insider's perspective of the experience and process of transition for people with autism during the stages of emerging adulthood. You are invited to participate in an interview which will take approximately an hour. You will not receive any financial benefit for the interview.

To assure confidentiality of your participation in the research, participant's anonymity will be ensured so that no one except the interviewer can identify any interviewee personally. All data collected from the study will be securely stored in the offices at the University of Saskatchewan by my supervisor, Professor Nazeem Muhajarine for a minimum of five years and will then be destroyed. I would like to assure you that my study will adhere to research ethics protocols and it has been approved by the University of Saskatchewan Behavioral Research Ethics Board. Your participation is voluntary, and you may withdraw from the study anytime you wish.

If you have any further inquiries please contact me or my supervisor at the address below. Thank you for considering being involved in this study.

Sincerely,

Ezajul Hoque Chowdhury

Contact Information

Researcher:

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6.4 Appendix D: Interview Guide for Parents

Demographic Information:

Age :
Sex :
Education :
Employment :
Diagnosis :
Interview place :

1. Tell me about the main changes that have happened in child's life during her/his transition to adulthood.
2. What kind of support are you getting from service providing organizations during your transition?
3. What are your expectations (the existing gaps) in service provided by the organizations and how can they help you in addressing your expectations?
4. What changes can the organizations make in their program to address your needs?
5. Is there anything that you might not have thought about before that occurred to you during this interview?
6. Is there anything else you think I should know to understand your transitional need better?
7. Would you like to ask me anything?

6.5 Appendix E: Interview Guide B for Professionals, Researcher, and Policy Makers

Demographic Information:

Age :
Sex :
Education :
Employment :
Interview place: :

1. Tell me about the services you are providing from your organization for people with autism.
2. What are their transitional needs that you are addressing?
3. Do you believe that service organizations can successfully address the transitional needs for people with autism? If not please elaborate.
4. Do you have any ideas that may help to address transitional needs in a more effective manner? If yes, please elaborate.
5. How well are the services for autism through organizations coordinated? Please provide your recommendations.
6. Is there anything that you might not have thought about before that occurred to you during this interview?
7. Is there anything else you think I should know to understand your transitional needs better?
8. Would you like to ask me anything?

6.6 Appendix F: Certificate of Completion the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Course of Research Ethics

